HNC Sends Gifts to Honduras

Each year at the Holiday Celebration, it’s a time for HNC members to “pay it forward” to others and bring items to the event that will benefit another charity. At the most recent event, attendees were asked to bring small items to donate to Save One Life. Save One Life is an international non-profit organization that helps people in developing countries living with bleeding disorders.

Small boxes of Legos, various toys, squeeze balls, crayons, toothbrushes, and toothpaste were collected from HNC members at the event and shipped to the Save One Life office. The next scheduled trip for Save One Life was to Honduras where HNC’s donations were distributed during a chapter meeting in Tegucigalpa. The children and their families were very excited to receive the items. During the trip, Heather Klee from Save One Life had the opportunity to make some home visits. Heather shared that when she went to the first home, the small Lego toys that the boys had just received the evening before were the only toys or personal items she saw in the home. Imagine how cherished those toys will be.

After each of the beneficiaries at the meeting received a toothbrush, the remaining toothbrushes were given to the dentist at the hospital in Tegucigalpa that works with the hemophilia chapter. In a meeting, the doctor told Heather that a 30 year old man had died the previous week from a bleed resulting from him pulling out a rotten molar. The man did not realize that he had hemophilia and waited for several days to go to the hospital. By that point, it was too late. The doctor explained her efforts to encourage good dental health to prevent gum bleeds, and she will be sending her hemophilia patients home with the toothbrushes and toothpaste that were sent by HNC.

As Americans, it can be difficult for us to envision a situation where a toothbrush and toothpaste can make such an important difference to a person with a bleeding disorder. HNC giving back means so much to the bleeding disorders community in Honduras. If you know of a dentist in your town who might want to help HNC make a difference to people in developing countries who have bleeding disorders, please tell them this story and ask them if they can donate some extra toothbrushes for HNC’s next collection.

Thanks HNC members for making a difference!
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 of NC
(919) 554-3272 (Collect)
www.healthcharities.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 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
Fax: (252) 744-8199

St. Jude Affiliate Clinic at Novant Health
Emby Children’s Hospital
Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Treatment Center
UNC Hemophilia and Thrombosis Center
University of North Carolina at Chapel Hill
Campus Box #7016
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

Wake Forest University Baptist Medical Center
The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

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

Inalex Communications
201-493-1399
www.inalex.com

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

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

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

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

About This Publication
THE CONCENTRATE is the official newsletter for Hemophilia of North Carolina. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

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.

Additional Medical Resources
Carolinas Medical Center
Pediatric Hematology/Oncology
1000 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 381-6800

Duke University Medical Center
Hemostasis and Thrombosis Center
DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-5350
htc.medicine.duke.edu

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.
Meet HNC’s Newest Board Members

HNC held the election for its Board of Directors at the Annual Meeting on March 10 in Winston-Salem and would like to welcome newly elected Board members Kelly Cribbs, Tiffany Hargett, Kathy Register, Michelle Vanhook, and Bryant Windham. 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, 2018. It’s with great appreciation that we say thank you to Michael Hoernlein and Arlette Whitaker for the time and commitment they’ve given to HNC and the members of this community.

Kelly Cribbs
A native of Gastonia, North Carolina, Kelly currently resides in Wake Forest, calling the Triangle region home. She and her husband, Malcolm, have been married for 12 years and are the proud parents of three boys; Brandon 10, Braylon 7, and Bryson 5. Both Brandon and Braylon have severe hemophilia (Factor IX) and have battled inhibitors; however, with a strong family support system and a wonderful team at the UNC Hemophilia Treatment Center, Kelly has been able to navigate the exciting and challenging world of bleeding disorders. Kelly has been a member of Hemophilia of North Carolina since 2008, serving on the NC Advisory Board for Bleeding Disorders, HOPE committee, Scholarship and Advocacy committees, and as an advocate during NC Legislative Day and Washington Days on Capitol Hill. Kelly is also a member of The Autism Society of North Carolina, which advocates for those in the Autism/special needs community. Kelly currently works within the clinical research industry as a pharmacovigilance specialist where she is a project lead on various NIH sponsored clinical trials. She is also finishing her graduate degree in pharmaceutical science at North Carolina Central University where she is a member of the International Society of Pharmaceutical Engineers. Kelly holds her Bachelors of Science in Biology and minor in Psychology from Hampton University in Virginia. In her spare time, Kelly and her husband are culinary explorers with a passion for traveling. She also enjoys spending time on her most recent interest, gardening.

Tiffany Hargett
Tiffany was born and raised in Guilford County, NC, and attended University of North Carolina at Greensboro where she received her BS in Sociology with a Concentration in Criminology. Tiffany is married to Brandon and together have three sons, Nick, Zack, and Kam along with two furbabies; Jackson and Bay. After graduating from UNCG, Tiffany moved to Clemson, SC, to be with Brandon while he finished college and worked with Mental Health as a counselor at a group home. Once Brandon graduated, they moved back to NC and got married. Shortly after marriage Nick was born. Then, Zack was born in September of 2008 and at 5½ months old was diagnosed with Hemophilia A; Severe. At 9 months he was diagnosed with an Inhibitor, and shortly after that Tiffany found out that she’s a carrier. The Hargetts have been involved with Hemophilia of NC for 9 years, attending Washington Days for seven years now and it’s one of their favorite things to do. They try to make it to Legislative Days and other HNC events as much as possible, whenever they don’t have sports. All three of the Hargett boys truly believe they are family with everyone in this tight knit community. Tiffany now resides in Colfax, NC, with her family and is very excited to be on the board, looking forward to what the future of HNC has in store.

Kathy Register
Kathy is returning to the HNC board after a six-year hiatus. She has been an officer or board member (most recently treasurer) on and off since the mid 1970s. She and husband Charles (severe factor VIII deficient) have stayed involved—Charles as HNC’s volunteer webmaster—and both of them (at different times) as volunteer Interim Executive Director, and as captains of the Family Festival Clot Hoppers Team. They both currently serve on the NC Advisory Board for Bleeding Disorders. Kathy and Charles reside in Durham, NC. They have two grown sons and two adorable granddaughters, ages 8 and 10.

Continued page 18
April 17 is World Hemophilia Day and HNC will be commemorating this day of building awareness about bleeding disorders around the world with an event at the Embassy Suites in Uptown Charlotte, NC. Did you know globally 1 in 1,000 people have a bleeding disorder? Most are not diagnosed and don’t get treatment. Through World Hemophilia Day events, HNC can support the World Federation of Hemophilia in their effort to change these statistics, raise awareness, and increase the support for those living with a bleeding disorder around the world.

HNC will be partnering with Bioverativ to light up a building red in Charlotte, raise awareness for hemophilia and other inherited bleeding disorders, and to honor our history and the progress within our community. There will be a family-friendly event for members of Hemophilia of North Carolina and Hemophilia of South Carolina with dinner and activities for members of all ages. Please visit the HNC website for more details.

If you can’t make it to Charlotte, you can do your part to help spread awareness by wearing red on April 17 and telling those you meet that you’re wearing red for bleeding disorders.

Charlotte Family Festival & 5K Walk for Bleeding Disorders
April 14, 2018
Mint Street at 3rd St. & MLK Blvd.
Uptown Charlotte, NC

The Charlotte Family Festival & 5K Walk for Bleeding Disorders is just around the corner, so if you haven’t already registered, please do so today!

You can expect some of the same fun activities as in past years along with some new ones your family is sure to enjoy. Kevin McVerry from Performance DJ will be back spinning some great tunes to keep the crowd energized, and Jecoreiography will be entertaining us with some great dance moves. We’ll have a head-to-head basketball shooting game for those who want to show off their skills. There will be plenty of other entertainment for people of all ages, so bring your friends, family, co-workers, and 4-legged friends for a great day of fun, festivities, and a 5K walk!

As in the past, the Festival’s success depends on the support of Walk teams, individual fundraisers, and sponsors in order to reach our fundraising goals! All money raised stays right here in North Carolina. As our largest fundraiser, the Family Festivals & 5K Walks in Charlotte and Raleigh benefit HNC members by providing critical funds needed to offer programs and services to our state’s bleeding disorders community.

Be sure to visit the HNC website for more information about the HNC Family Festival & 5K Walks and for directions on how to register and set up your team. Contact the HNC Office at (800) 990-5557 or email festival@hemophilia-nc.org if you have any questions or want additional information about this fun event.
HNC Open House: for All Community Members
May 5, 2018
Morrisville, NC

HNC will be holding an Open House on the afternoon of May 5 at the HNC office in Morrisville. This social gathering will be open to all HNC members as a way to connect the people of the community with one another at a relaxed get-together. There will be a pot-luck luncheon, so those who attend should plan to “bring a dish” to share.

Registration for this event and additional details will be available soon on the HNC website. In the meantime, if you have questions please contact the HNC office.

70th NHF Bleeding Disorders Conference
October 11-13, 2018
Orlando, FL

National Hemophilia Foundation’s (NHF) 70th Bleeding Disorders Conference will be held October 11 - October 13, 2018 in Orlando, Florida at the beautiful Orlando World Center Marriott. This conference is three days full of educational sessions, networking opportunities, and exhibit hall access. Registrations include entrance to the Opening Session, Awards Luncheon, and the exciting Final Night event. Childcare is available for children under 12 years old. Visit www.hemophilia.org to register and for more information about the event.

While it is a considerable commitment of time and money, HNC would encourage all members to make the effort to be part of this event. For more information about travel grants and registration, please contact the HNC office.

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HNC Blood Brotherhood Retreat
June 22-24, 2018
Pine Knoll Shores, NC

The Blood Brotherhood Retreat is a great opportunity for adult men (18+) with a bleeding disorder to connect with others who also have a bleeding disorder. Whether you’re new to the Blood Brotherhood or you’ve been a member for years, you’re invited to join the HNC Blood Brotherhood Retreat from June 22-24 at the Trinity Center in Pine Knoll Shores, NC.

The weekend will feature an agenda that allows plenty of time to get to know each other, make connections, and catch-up with old friends. You’ll also get to enjoy the beach!

HNC Men’s Retreat for ALL Men in the Community
July 20-22, 2018
Blowing Rock, NC

The men of HNC are headed to the mountains for a weekend retreat designed to support all men in the community through mentoring and common connections.

Save the date for the 4th Annual Men’s Retreat. If you are an adult male who has a bleeding disorder in your family, whether you have one yourself, or you are the parent or spouse of a person with a bleeding disorder, this retreat is for you!

Registration and information about upcoming events is available on the HNC website as events are nearing. Please check the website at www.hemophilia-nc.org, call the office at (800) 990-5557, or email us at events@hemophilia-nc.org for more information or to register.

We look forward to seeing you!
HNC Latin Union Roundtable

December 2, 2017
Greenville, NC

Following the HNC Holiday Celebration, a group of HNC’s Latin Union Program joined together for an afternoon of fellowship and conversation. The children were busy playing hide and seek while the adults and teens had a lively discussion about the Latin Union Program. From talk of the programs that they enjoyed in 2017 to what they would like to see from the Latin Union in 2018, everyone was full of ideas and suggestions. The discussion also included ways for HNC staff to find more resources to support the Latino community and volunteers for translating articles, invitations, and making phone calls to Spanish speaking members of HNC. HNC staff also explained the different services that we offer to the community including Financial Assistance and MedicAlert IDs. Following the program, everyone wished each other Happy Holidays and went off to enjoy the rest of their afternoon. We would like to thank Shire for providing a grant to support the Latin Union Program in 2017.

HNC Bowls a Strike

December 16, 2017
Cary, NC

On Saturday, December 16, HNC held an afternoon of bowling and education at Buffaloe Lanes Family Bowling Center in Cary, NC. As everyone arrived people were able to enjoy games including air hockey, ping-pong, and pool. Shortly after, pizza, wings, and other appetizers were brought into the room for a very filling lunch. Chris Ingram presented, *Lanes Not Divided: My Journey with Hemophilia*, where he detailed his love for sports including baseball and bowling. With target joints, he shared his experience of the importance of prophylaxis and taking care of himself so that he wouldn’t miss bowling tournaments and other events. He brought several of his rings from different bowling tournaments to share with the group. Following the presentation, everyone had the opportunity to try out bowling for themselves. The fun and excitement was evident as people cheered for their friends and family.

This program was an educational presentation part of HNC’s HOPE Program for families with children with bleeding disorders. Thank you to Octapharma for sponsoring this event.

HNC Blood Brothers Warm-Up at the UNC Pool

January 13, 2018
Chapel Hill, NC

At their winter gathering, the HNC Blood Brotherhood group learned about the value of aquatic exercise during their afternoon with Jennifer Newman, PT, UNC Hemophilia Treatment Center. The first stop was Tobacco Road Sports Cafe where everyone enjoyed lunch while also discussing in detail all the dos, don’ts, and what you need to know before embarking on this type of exercise. First and foremost, individuals should discuss their interest in beginning any new exercise program with their HTC Team to find out if it is right for them. Keep in mind that you should not swim if you have an active bleed, if you have a port or any central line (Ex: PICC) that is not de-accessed, uncontrolled seizures, or an open or healing wound. Also, keep your own swimming abilities in mind when deciding at what level your aquatic exercise program should begin. If done correctly and with the appropriate amount of oversight from your physical therapist, aquatic exercise has many advantages over other kinds of exercise.

The benefits of aquatic exercise, especially for people with joint pain, are plentiful. Some participants enjoy the environment of the pool’s “zero-gravity” effect, so they can strengthen their muscles without impact to joints. The warmth of a heated pool can also help with creating a low stress environment so you can get the most out of your exercise experience. A key point to keep in mind is when exiting the pool, do so gradually to avoid the discomfort that can accompany a more sudden re-entry into normal gravity.

Once the Blood Brothers learned all they needed to know about what to expect, it was time to go to the pool. The pool at the UNC Wellness Center at Meadowmont in Chapel Hill is a heated pool where Jennifer led the group through the basics of aquatic exercise. Regardless of whether this was their first time in the pool or they were experienced swimmers, all who participated agreed that it was a great time.

If you have questions or want to find out more about how aquatic exercise can benefit you, contact the physical therapist at your Hemophilia Treatment Center.

THE CONCENTRATE

Spring 2018
Hemophilia of North Carolina (HNC) hosted the 11th annual “Hearts for Hemophilia” Casino Night event in Durham on Saturday, January 27, at the Durham Convention Center. The crowd was lively and the atmosphere vibrant with live music, wonderful food, casino games and, the exciting live and silent auctions. The games included blackjack, craps, Texas hold ‘em poker, and roulette. With each guest starting out with $10,000 of “fun money”, it was a good time for all win or lose.

The silent auction table was filled with a variety of gifts including: a family getaway to Great Wolf Lodge, Museum Tickets to Marbles Kids Museum, Durham Museum of Life + Sciences, and Kidzu Children’s Museum, NC Attractions and Activities like the NC Symphony, Daniel Stowe Botanical Gardens, the Great Raleigh Trolley, Brunch at Fearrington Village, Vintage Navajo Turquoise Jewelry, Wine Tasting at Triangle Wine, Gift Cards to restaurants at Parkside Town Commons in Cary, Artwork from Modern Art by Dan Campbell, Tim Postell, Veronica Samuel, and Diane Johnston, themed gift baskets, and more!

With the help of Auctioneer Patrick Kinas, Play-by-Play Announcer for the Durham Bulls, the evening’s live auction for the Golf Getaway for Four at Sea Trail Resort in Sunset Beach, NC, the Carolina Panthers Lithograph Signed Football, and the Bluegreen Vacations Weekend in Gatlinburg TN, Pigeon Forge TN, or Myrtle Beach SC, was filled with excitement. Of course, the most meaningful part of the live auction was the opportunity to make a bid of financial contribution to our emergency assistance program, an important part of HNC’s mission to support the bleeding disorders community.

New this year was the chance to win the Grand Prize Raffle trip to anywhere. With an opportunity to purchase raffle tickets, one lucky winner went home with two round-trip tickets on Southwest Airlines and two Wyndham Worldwide standard hotel nights.

Even if guests didn’t win the grand prize or auction, there were other opportunities to win with door prize raffle items. If your luck ran out, you didn’t go home empty-handed as each attendee received a souvenir cup and a deck of cards as a thank you for supporting HNC. HNC raised over $23,000 at this year’s “Hearts for Hemophilia” Casino Night and all proceeds will help to continue the goal of improving the quality of life for those affected by a bleeding disorder. Through fundraising events such as this, HNC’s vision for everyone to achieve their full potential without barriers or limitations becomes closer to becoming a reality.

The HNC Board of Directors would like to acknowledge the hard work and tireless effort of many that helped make this event possible, especially the Casino Night Committee members, Tiffany Holland, Diane Johnston, Xaviette Pointer-Kincy, and Michelle Vanhook. Thanks to our entire list of sponsors, donors and individuals who came out to support for continuing the casino night tradition!
Educational Dinners Around the State

HNC encourages members to attend educational dinners in their area as a way to learn more about living with and navigating through life with a bleeding disorder and to meet others in the community. If there is a topic of interest you wish to be brought to your area of the state, please contact the HNC office.

The Challenges of Living with a Bleeding Disorder as a Family
February 10, 2018
Raleigh, NC

HNC and CSL Behring partnered for the presentation for the entire family, with a focus on women and girls with bleeding disorders. Kristin Prior spoke about her personal journey and the challenges of living with a bleeding disorder, for those affected as well as their caregivers. She shared her insights and spoke about how community connections through her local chapter have impacted her family’s lives. After the presentation, the families in attendance spent time meeting and getting to know other HNC members to develop those community connections for themselves.

Dealing with Persistent Pain
February 22, 2018
Raleigh, NC

HNC partnered with Pfizer Hemophilia for the program Considerations for the Bleeding Disorder Community: Dealing With Persistent Pain at Winston’s Grille in Raleigh, NC. Linda Pollhammer, Patient Affairs Liaison for Pfizer, led a dynamic discussion about how to manage persistent pain. The conversation was beneficial not only to those who have pain related to bleeding disorders but also to family members in attendance who experience chronic or persistent pain related to other conditions. People shared their own ways of managing pain and brought up topics related to pain management that others in attendance could discuss with their healthcare professionals for their own treatment.

HNC is thankful for the corporate partnerships that help make these educational dinners possible.

Team Captain Meeting for Charlotte Festival & 5K Walk
February 24, 2018
Charlotte, NC

The 2018 HNC Charlotte Family Festival & 5K Walk for Bleeding Disorders is around the corner. On February 24, it was the perfect day to get together some returning and new team captains to discuss the event and share ideas on fundraising. Attendees left with new ideas, resources to help them in their efforts, and of course some HNC piggy banks to help them kick off their fundraising efforts.

Raleigh Team Captains: Be on the lookout for a Team Captain Meeting near you as we get a little closer to the 11th annual Raleigh Family Festival & 5K Walk for Bleeding Disorders, taking place on September 15.
Actualización de la Unión Latina

Hemofilia de Carolina del Norte esta muy animada con todo lo que se ofrecerá a través del Programa Unión Latina durante el año 2018. El primer evento se llevó a cabo en la Reunión Anual, el 10 de Marzo; donde varias familias tuvieron la oportunidad de obtener información acerca de planificación financiera. El 24 de Marzo, la Unión Latina gozó de un almuerzo en Dave & Buster’s en Concord y los asistentes tuvieron la oportunidad de jugar en la arcada, después del almuerzo. Otras fechas destacadas para el 2018 son: 2 de Junio, 11 de Agosto, y 1 de Diciembre siguiendo las festividades de fin de año.

HNC está muy emocionada de anunciar el primer Retiro de la Unión Latina, el 28 y 29 de Julio, en Winston-Salem.

HNC Mesa Redonda de la Union Latina

2 de Diciembre, 2017
Greenville, NC

A continuación de la celebración de Fiestas de Fin de Año del HNC, un grupo de miembros del programa Unión Latina, se reunieron para disfrutar de una tarde de compañerismo y conversación.

Mientras los niños estuvieron ocupados jugando al escondite, los adultos y adolescentes mantuvieron una animada discusión acerca del programa HNC Unión Latina. La conversación abarcó desde las actividades realizadas el año 2017 hasta las expectativas para la agrupación durante el 2018; cada uno aportó ideas y sugerencias. La discusión también incluyó distintas formas para que el personal del HNC pueda conseguir más recursos para apoyar la comunidad latina y también reclutar voluntarios para traducir artículos e invitaciones, y hacer llamadas telefónicas a miembros de habla hispana del HNC. De la misma manera, el personal del HNC enumeró los distintos servicios ofrecidos a la comunidad, incluyendo Asistencia Financiera y tarjetas de identificación de MedicAlerts.

A continuación, hubo intercambio de saludos, se desearon Felices Fiestas y luego disfrutaron del resto de la tarde.

Quisiéramos agradecer a Shire, por facilitarnos realizar esta celebración y por el constante apoyo al Programa Unión Latina durante el año 2017.
Charlotte Family Festival & 5K Walk for Bleeding Disorders
14 de Abril, 2018
Charlotte, NC

The Charlotte Family Festival & 5K Walk for Bleeding Disorders (enfermedades hemorrágicas) ya viene! Si aun no se ha registrado, no demore más y por favor hágalo hoy!

Les anticipamos que habrán algunas de las mismas actividades ofrecidas el año pasado y también otras nuevas que de seguro su familia disfrutará. Kevin McVerry de Performance DJ estará de vuelta, deleitándonos con melodías y canciones siempre favoritas que energizaran a la audiencia; y Jecoreiography nos entretendrá con sus amenas coreografías y bailes. Habrán muchas otras entretenencias para todas las edades, así es que no deje de invitar a sus amigos, familia, colegas, así como también sus mascotas de 4-patas a disfrutar de un gran día de entretenimiento, festividades y una caminata de 5K!

Como en ocasiones anteriores, el éxito del Festival depende del apoyo que reciban los Equipos de Caminata, los recaudadores de donaciones y los auspiciadores, a fin de lograr nuestros objetivos de recolectar fondos! Todo el dinero que se logre reunir quedará aquí en el estado de North Carolina. Nuestros mayores auspiciadores son el Family Festival & las Caminatas de 5K organizadas en Charlotte y Raleigh que benefician miembros de HNC contribuyendo con fondos básicos para proveer programas y servicios a los residentes de nuestro estado, que sufren de enfermedades hemorrágicas.

No deje de visitar el sitio web de HNC, donde encontrara mas información acerca del HNC Family Festival & 5K Walks, además de instrucciones para inscribirse y preparar a su equipo. Por favor contáctese con la oficina de HNC al (800) 990-5557 o email festival@hemophilia-nc.org, en caso que tenga preguntas y otras consultas acerca de este entretenido Festival.

The hemophilia treatments of today were once the dreams of yesterday. Proof that when science and the community come together, great things happen.

Let’s put science to work GenentechHemophilia.com
SOAR Program Update

Did you know that the SOAR Program is for women and girls affected by bleeding disorders? The SOAR Program focuses its attention on educating and advocating for women and girls with bleeding disorders so that they can have a safe place to join together in sisterhood with other women and girls like them.

This year, the SOAR Program is growing in leaps and bounds! HNC will continue to host educational dinners and events like the one in February following the SOAR Fundraiser and the breakout session at the Annual Meeting on March 10. New in 2018, HNC will also be hosting a weekend SOAR Retreat on June 23-24. This is to build upon the Educational Day held last year. Listening to your feedback of wanting more time together, HNC is excited to expand the opportunity to a two-day event.

Did you know that HNC’s SOAR Program also advocates for correct diagnosis and treatment of bleeding disorders? SOAR will continue to work toward raising awareness at nurse’s conferences across the state and is very excited to have launched the Women’s Bleeding Disorders Coalition, as an arm of the SOAR Program. The Coalition’s focus will be to raise awareness and advocate for women and girls with bleeding disorders beyond what is already being done. You may have seen some postings on social media about the #DontBlush campaign. Please share these posts on your own social media platforms along with some of the facts about bleeding disorders in order to raise awareness about women and girls with bleeding disorders. HNC is continuing to work on other ways to get the word out, so if you have any ideas, please contact the HNC office.

SOAR is an HNC Program for women and girls with bleeding disorders. 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. Sessions are planned to support women with von Willebrand Disease, platelet disorders, and factor deficiencies including symptomatic hemophilia carriers and women with hemophilia.

For more information, or if you have an idea for an event, contact Gillian Schultz, HNC Program Manager at soar@hemophilia-nc.org or call the HNC office at (800) 990-5557.

Membership Information

For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to soar@hemophilia-nc.org.
HNC extends a special thank-you to all those who came out to support the SOAR Program for women and girls affected by bleeding disorders by attending the Wine & Cheese for SOAR fundraiser at Total Wine & More in Raleigh, NC.

The group learned about wines of Italy. From Prosecco to Chianti to Pino Grigio, attendees toured Italy’s wine region sampling eight different varieties of red and white wines while enjoying cheese, chocolate, and other snacks to accompany the wine. A special thanks to Nate Sentz, Wine Manager & Connoisseur, for his fun approach to wine. Whether you were new to wine or had already acquired an appreciation for it, everyone learned something new to enhance their knowledge. Best of all, it was a really fun way to get to know each other and share some laughs!

Proceeds from this event will be used to help fund HNC’s SOAR program, including support for attending nursing and other professional conferences around the state. Outreach and advocacy at professional conferences will help HNC’s SOAR program achieve its goal of increasing knowledge and awareness about the symptoms, diagnosis, and treatment among those professionals who might help decrease the time for proper diagnosis among women and girls with bleeding disorders.

Hemophilia of North Carolina gratefully acknowledges the following companies for their support of the 2018 SOAR Fundraiser:

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**Silver Sponsor**
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**JOIN IN HNC’S NEW SOCIAL MEDIA CAMPAIGN #DONTBLUSH**

to raise awareness about women with bleeding disorders. Contact the HNC office for copies of images to post on your own social media accounts or follow HemophiliaNC on Facebook, Instagram or Twitter to share #DONTBLUSH posts.
Teen Retreat: Carolina Crew Meets Again in July 2018!
July 5-8, 2018
Camp Canaan, Rock Hill, SC

Attention Teens (ages 13-18)! Save the date, July 5-8, 2018 for the next joint Teen Retreat with HNC and HSC, also known as the Carolina Crew (coined by teens back in 2013). Teens will head back to Camp Canaan in Rock Hill, SC, to enjoy a great weekend of fun and educational programming. GutMonkey will also return to lead teens in their Leading Edge program. Find out more about it at www.gutmonkey.com.

This is a fun, educational weekend designed especially for teens in the community. Teens who have a bleeding disorder or are the sibling or child of a person with a bleeding disorder are eligible to attend this retreat. The Retreat is a great opportunity to make new friends, share laughs, challenge yourself, and prepare for your future. If you’ve never been to one of HNC’s Teen Retreats, please check out the HNC Facebook page for photos.

HNC will provide busing from the ECU HTC in Greenville and the HNC office in Morrisville. Teens will be allowed to bring 1 friend or family member with them as long as that person is also a teen.

Kids and Teens at HNC’s 45th Annual Meeting
The Annual Meeting has something for everyone, including kids and teens. Here are some favorite moments from the day.
The 2018 Hemophilia of North Carolina (HNC) Annual Meeting was an exciting and impactful day for everyone who was able to attend. The event took place on Saturday, March 10, at the Embassy Suites in Winston-Salem. During the morning registration, attendees had the opportunity to grab some breakfast and meet the sponsors in the exhibit hall. The General Sessions started off with a flurry of excitement as Connie Montgomery from the National Hemophilia Foundation (NHF) captivated everyone’s attention with her *Patchwork Quilt* program. This was an interactive presentation to illustrate how everyone has their own individual strengths and experiences, but it is important for us to come together as one united community. As part of the program, each group created their own piece of a patchwork quilt which put together becomes a quilt for the community.

The theme of being one united community continued after lunch with a panel discussion about advocacy in the community. The panel featured Karla White, Director of State and Government Affairs with CSL Behring, Tara Britt and Sharon King from the Rare Disease Advisory Council, and HNC members Tiffany Hargett and Joseppe Vilchis. Together they shared their experiences advocating for bleeding disorders and other rare diseases, and talked about the importance of “singing as a choir” rather than with individual voices in order for everyone’s needs to be heard.

The day finished off with an exciting session led by Dr. Henry Mead from CSL Behring on treatments currently in development and in clinical trials. This session talked about gene therapy studies for both hemophilia A and B, as well as where scientists are in understanding how to treat von Willebrand Disease. It is an exciting time for the children of today as it may be possible that gene therapy that may essentially “cure” hemophilia will be available in their lifetime.

In addition to the general sessions, there were several breakout sessions. Donnie Akers, from the Hemophilia Federation of America
HNC Annual Meeting  continued from previous page

(HFA) led a session for the industry sponsors as well as a session for all HNC members, Standards of Care and Informed Consent in the Emergency Room where he shared some very valuable information that all patients should be aware of. Chelsea Frimpong of NHF led an interactive session, Do You Bleed Like Me?, which examined the similarities and differences between different bleeding disorders. Yinell Nunez from Shire led an important session in Spanish about financial literacy. There was a roundtable discussion about living with inhibitors led by HNC members Kelly Cribbs and Tashara Young. The day also featured breakout sessions for the HNC Programs: HOPE for families with children with bleeding disorders led by Gillian Schultz, HNC Program Manager, SOAR for women and girls with bleeding disorders led by Charlene Cowell, HNC Executive Director, Blood Brotherhood for adult men with bleeding disorders, led by Curtis Gray, social worker at the UNC-Chapel Hill HTC, and a session for partners & spouses led by Sara Ceresa from Octapharma to learn how to support one’s spouse with a bleeding disorder.

The HNC Annual Business Meeting was held where members heard about HNC’s financial health and had the opportunity to vote for members for the upcoming 2018-2020 term of the Board Directors. All members who were up for re-election were voted back in and five new members were voted onto the HNC Board (see page 3). In addition to programming for adults, there was a children’s and teen track for the day. Teens learned the importance of staying physically active, led by Physical Therapy (PT) doctoral student Ned Bixby who is currently working with Jennifer Newman, PT at the UNC-Chapel Hill HTC. They then learned about becoming independent as they develop into young adults, followed by a discussion of the NHF National Youth Leadership Institute (NYLI). Both sessions were led by Chelsea Frimpong, NHF and Dulce Siera, NYLI. The afternoon program, Clot Shots, was led by Melissa Carper and Rob Toledo of Diplomat. The teens learned about video editing and created a commercial that you can view on the HNC YouTube Channel.

Younger children participated in a day full of activities and educational sessions. They learned about their bleeding disorder in either the CVS Specialty Program Meet George, Therapeutic Play or Meet George, Recognizing Bleeds both led by Mimi Castaneda. The 9-12 year olds played Mousetrap to learn about the clotting cascade in Silly Science, led by Kayla Klein from Octapharma. The 4-8 year olds made slime and learned about blood in Factor Fun led by Diane Horbacz from Biomatrix. The afternoon included a close encounter with snakes and reptiles from Cold Blooded Encounters and a fun magic show. They also learned about the importance of giving back by creating “Kards for Kindness” which will be distributed to children who are in the hospital. They ended their day watching a movie. HNC’s youngest attendees were watched in the daycare program. Thank you to Providence Children for providing the childcare providers for the day.

A final thank you to the volunteers and members who contributed and helped make HNC’s 45th Annual Meeting a success. Save the date for the 2019 Annual Meeting for March 2, 2019 in Charlotte.
2018 Volunteer and Special Guest Dinner
March 9, 2018
Winston-Salem, NC

As it’s traditionally done in the past, HNC held its annual Volunteer and Special Guest Dinner the evening before the Annual Meeting. This year’s celebration of HNC’s volunteers and special guests took place at the Embassy Suites in Winston-Salem on March 9. HNC takes this opportunity each year to recognize and thank people who have dedicated their time and talent during the past year to helping HNC achieve its mission. Whatever their affiliation to the bleeding disorders community, these individuals went above and beyond on behalf of HNC and all HNC members.

Caroline Farmer, Executive Director of the North Carolina Commission on Volunteerism and Community Service from the Office of Governor Roy Cooper, gave an inspiring presentation called The Power of Giving Back: Why is it important? Through this presentation, attendees gained a greater understanding of how they are making a difference both within and outside of the bleeding disorders community.

HNC is grateful for all the volunteers who helped make its programs such a success in 2017. Moving into 2018, HNC hopes to continue to expand the use of volunteers, especially from members who have special training or talents they feel would benefit the organization. There are many ways people around the state can become a volunteer or contribute their talents to help HNC promote advocacy, education, promotion of research, and delivery of supportive programs and services. Whether you’re interested in helping with basic office work, translating documents, or helping to plan fundraisers, there’s a volunteer opportunity for you. If you would like to find out how your skills might benefit the community, please call the HNC office (800) 990-5557 or email info@hemophilia-nc.org for additional information.

Guest speaker, Caroline Farmer

Volunteers and special guests gather to celebrate their contributions to HNC

2018 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2018. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

General Donations
Irene Cowell
Lois Geer
Mr. & Mrs. W. Allen Heafner
Sandra Ogburn
Susan Olive
Daryl Steinbraker
Penni Tharp
Sobha Valamani

In Memory of Thomas Gordon
Kathy White

George D. McCoy Scholarship Fund:
Emily Balance
Karen McCoy
Phillip Poovey
Christy Spain
Paul & Emily Wilson

In Memory of Thomas Rodgers, Sr.
Kimberly Battenberg
Brenda & Ernie Laferriere
Mark & Molly Whitehouse

In Celebration of Kathy Register’s Birthday
Linda Convissor
Harriet Sayre-McCord

SOAR Fundraiser:
Charlene Cowell
Karyn & Kyle Davis
Andrew & Bonnie Gullett
Tiffany Holland
Kelly Hoots
Jecorei Lyons
Heather Nassaur
Gillian Shultz
Amy Shair
Ann Skinner
Miriam “Michelle” Vanhook
A North Carolina native, born and raised in Scotland County, Michelle received a BS in Biology, with concentration in Molecular Biology from Winston-Salem State University and a MS in Biology from North Carolina Central University. She currently works as a Project Manager in Regional Research Clinical Trials at LabCorp where one of her projects involves FVIII and FIX testing in support of a post market hemophilia program. Michelle became involved with Hemophilia of North Carolina as a walk volunteer through her good friend Tyronna Hooker and her sons, both living with the disorder. She has a creative, energetic spirit and warm personality with a genuine desire to help others. When free time allows, Michelle enjoys baking and entertaining. Most of her non-working hours are spent doing extracurricular activities with her husband of 17 years, their 12 yr old son Jared, 3 yr old fur baby Roxi, and their newest addition, 8 yr old horse Carter.

Bryant Windham
Bryant is a native of Detroit, Michigan. He relocated to North Carolina in 2010. Bryant has a degree in business and marketing from Northwood University and a MBA from Keller Graduate School of Management. He currently works as a Project Coordinator for Syneos Health. He will look to leverage his years of marketing, project management and leadership experience to benefit HNC. Bryant has a true desire to serve his community and help shape the minds of our youth. He has worked with the Kappa Foundation of Cary through heading up their youth leadership program and volunteered with the Food Bank of NC through the White Oak Foundation. Bryant lives in Raleigh with his wonderful wife, daughter, and son. He enjoys college football, spending time with family, and mentoring. Bryant looks to bring his passion of service to HNC and believes that promoting awareness of bleeding disorders in our communities’ aides in the quality of life for persons affected and their families. He has no relationship with hemophilia or other bleeding disorders.
Join the HNC Blood Brotherhood for events around the state in 2018! 2018 started off with a great gathering of Blood Brothers in Chapel Hill with Jennifer Newman, Physical Therapist at UNC-Chapel Hill, at the Blood Brotherhood Winter Warm-up. Blood Brothers also gathered at the HNC Annual Meeting in Winston-Salem on March 10, with a session called Connecting Generations, facilitated by Curtis Gray, Social Worker at UNC Chapel Hill. Moving through 2018, the Blood Brotherhood program continues to reach men around the state by hosting two additional one-day gatherings in locations of NC that haven’t had Blood Brotherhood meetings in the past. These are currently scheduled to take place in Lumberton on September 29 and in Hickory on December 15. In addition to these one-day gatherings, Blood Brothers should mark their calendars for two retreats in 2018. June 22-24 – HNC BB Retreat – Trinity Center at Pine Knoll Shores, NC July 20-22 – HNC Men’s Retreat – Blowing Rock Conference Center at Blowing Rock, NC HNC’s Blood Brotherhood is an extension of HFA’s Blood Brotherhood Program. It’s designed to provide opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. If you can’t make an event consider connecting with adult men with bleeding disorders from the comfort of your own home with the new and improved Blood Brotherhood private online forum! Go to www.hemophiliafed.org to register.

Hemophilia of North Carolina is excited about all that will be offered through the Latin Union Program in 2018. The first event was held at the Annual Meeting on March 10 where several families were able to learn about financial planning. On March 24, the Latin Union gathered for lunch at Dave & Buster’s in Concord and everyone had the opportunity to play in the arcade after the lunch. Other Latin Union educational dates for 2018 are: June 2, August 11, and December 1 following the Holiday Celebration. HNC is very excited to announce the first ever Latin Union Retreat on July 28-29 in Winston-Salem. This weekend event will feature educational programming entirely in Spanish. The details are still being finalized, so keep eyes open for information about the Latin Union Retreat.

The Latin Union is an HNC Program designed 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 Shire. For more information, visit the HNC website.
NC HTC Physical Therapists Meeting
February 18, 2018
Morrisville, NC

North Carolina HTC Physical Therapists got together on February 18 at the HNC office to spend time connecting and exploring Musculoskeletal Ultrasound. Pictured are Jennifer Newman (UNC) and Lora Joyner (ECU) deepening their knowledge of using ultrasound at their respective clinics. Musculoskeletal ultrasound is helping HTCs to better identify and treat joint and muscle bleeds.

Guidelines for Emergency Department Management of Individuals with Hemophilia and Other Bleeding Disorders

On September 17, 2017 the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) approved a new document for individuals with bleeding disorders who go to an emergency department for care to assist them in receiving appropriate and expeditious management. The guidelines outline steps to help families who need emergency treatment to assist them with properly discussing their needs with the healthcare provider and manage the patient’s care through their Triage, Assessment, Diagnostic Studies, Indications for Factor Replacement Therapy, and Treatment at the emergency room. To read or download this and other MASAC documents, visit https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC.

Want to Know More about your factor options?

When it comes to your factor therapy, you have choices. And at Bioverativ, we recognize the importance of continued research as well as supporting the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

To learn more about these options, contact your CoRe Manager:

Tanya Stephenson  |  Phone: 781.663.1875  |  E-mail: tanya.stephenson@bioverativ.com
ON THE NATIONAL & LEGISLATIVE FRONT

Advocating for Access in DC

March 7-9, 2018
Washington DC

By: Zack Hargett, age 9, and Charlene Cowell

It was a quick couple of days as 17 Hemophilia of North Carolina (HNC) members took to Washington DC to advocate for the bleeding disorders community. NHF’s Washington Days is an excellent opportunity for the community to speak with their representatives about issues that are important to them.

This year the two big talking points involved access to healthcare and maintaining funding for the Hemophilia Treatment Centers (HTCs). With all the proposed changes to healthcare it is important that people with bleeding disorders are able to maintain adequate coverage. For example, there is currently a ban against lifetime caps. Some may remember the days before this, when a person may exceed their insurance policy and their care would no longer be covered under their insurance. While in DC, advocates explained why it is important for the ban on lifetime caps to remain intact for any health care bill. It is also vital that the protections for those with pre-existing conditions remain so these individuals can get coverage to keep them healthy, productive citizens. There is also concern that HTC funding may be in jeopardy. The comprehensive care the HTCs offer are essential. As more people are being diagnosed with bleeding disorders and patient populations are growing, the HTCs need to have the funding to keep up.

With nine meetings, it was a busy and productive day on Capitol Hill. For anyone who has never been, there is no better time to start advocating for you and your loved ones. Interested in getting involved in advocacy or learning more about this year’s talking points? Call the HNC office at (800) 990-5557.

HNC Legislative Day: It’s for Everyone!

June 13-14, 2018
Raleigh, NC

Have you wondered who would be the best person to advocate for people with bleeding disorders? That person is you!

All members of this community have one thing in common regardless of age, type of bleeding disorder, role in the community, or political views. Every member is called to stand as watchdogs for you as an individual, our families, and our community on topics that may have an impact on those living with bleeding disorders.

With that in mind, HNC asks that you come out to represent your State Legislative District at the HNC Legislative Day in Raleigh this year on Thursday, June 14. One continuing focus of the annual HNC Legislative Day is to keep on building awareness and relationships among our North Carolina State Representatives and the bleeding disorders community throughout the state. The landscape of our healthcare system and other state services continues to change, so as we get closer to the date, the HNC Advocacy Committee will determine what specific issues may impact people affected by bleeding disorders in NC. HNC’s Legislative Day is a perfect opportunity to meet House and Senate members and use YOUR voice and YOUR story to remind our legislators to consider the bleeding disorders community when making important decisions on behalf of the residents of their district.

There will be a training session and dinner the evening of Wednesday, June 13, with hotel accommodations available upon request through May 11 for attendees traveling over 30 miles who will also attend the training.
Advocating for HR 3976 in DC
December 12-13, 2017
Washington, DC

It was a quick trip to Washington DC with Patient Services Inc. (PSI) in December but quite a full day of advocacy. Within six hours James Romano (PSI), Dana Kuhn (PSI), and Charlene Cowell (HNC), visited ten congressional offices. The focus of the trip was on the Access to Marketplace Insurance Act (HR 3976), a bipartisan legislation that would require health insurance companies to accept payments from non-profit organizations that operate in compliance with the False Claims Act. Unfortunately, in 2014 the Centers for Medicare & Medicaid Services (CMS) did not include non-profit charities on the list of entities that can provide third-party assistance for patients. The result is that health plans are able to, and in many states have, denied coverage for patients by rejecting the premium and cost-sharing assistance they were previously receiving from non-profit third parties like PSI.

As of March 1, there are 116 cosponsors for HR 3976. There is still much work to be done in order to ensure that individuals are not denied coverage because of this CMS oversight. If interested in advocating for HR 3976, or if you have questions, please contact the HNC office at info@hemophilia-nc.org or (800) 990-5557.

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 advocates-subscribe@hemophilia-nc.org or calling the HNC office at (800) 990-5557 to get involved!
## Hemophilia of North Carolina 2018 Calendar of Events Highlights

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<td>World Hemophilia Day Event</td>
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<td>June 22-24, 2018</td>
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<td>December 15, 2018</td>
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## Donate to HNC

Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. *Your dollars make a difference.*

**Name:** ____________________________________________

**Address:** __________________________________________

**City:** ____________________________  **State:** __________  **Zip:** __________

**Home Phone:** ____________________________  **Cell Phone:** ____________________________

**Comments:** ________________________________________

**Amount:** ____________________________

Please make checks payable to Hemophilia of North Carolina. We are a 501c(3) non-profit organization, so your donation will be tax deductible to the extent allowed by law. We will send you a receipt for tax purposes.

You may also donate online at [www.hemophilia-nc.org](http://www.hemophilia-nc.org) with your credit card.  

Thank you!
Join Hemophilia of North Carolina (HNC) for its annual Family Festival and 5K Walk, fundraisers dedicated to preventing the complications of bleeding disorders.

All proceeds help us continue our education, advocacy, and peer support programs and services to our North Carolina community. Your support and participation ensures that the enthusiasm and impact of Hemophilia of North Carolina will make a difference across the state!

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.

Mint Street at 3rd St. & MLK Blvd.
Uptown Charlotte, NC

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

5K / 3.1 Miles or
2.4K / 1.5 Miles (short route)