We Remember…
George D. McCoy
1947-2017

By: Kathy Register, HNC Member

Hemophilia of North Carolina lost its key founder and friend with the passing of George D. McCoy. George was on hand, and often in charge, in the early 1970s and beyond as our little organization materialized and grew in fits and starts. He has been present every step of the way, until his death August 23 at the age of 69. On March 4, George was elected to our board of directors, only to step down when he took ill shortly thereafter. He would be the first to tell you he defeated his lifelong sparring partner, hemophilia, when he succumbed to pancreatic cancer instead.

At the time of his death, George was a leading intellect and wit not only on our board, but as a Blood Brotherhood leader and mentor, and as a thinker and an intelligent spokesman for our advocacy efforts in Raleigh and Washington. He also sat on the North Carolina Advisory Board for Bleeding Disorders.

This diminutive giant was a presenter at the World Federation of Hemophilia Congress in Paris in 2012, and over the years rubbed elbows with the likes of Rosalyn Carter,

HNC Takes Home Two Awards!
August 26, 2017
Chicago, IL

There is a lot going on around the country by state chapters whose mission is to support those affected by bleeding disorders. Creative and innovative programming, events, and outreach were celebrated at National Hemophilia Foundation’s (NHF) 69th Annual Meeting in Chicago during an award ceremony that took place on the final day of the conference. Chapter Recognition Awards of Distinction were presented in

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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 supportive programs and services.

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

An electronic version may be found on the HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

We maintain a membership mailing list. However, we never release any personal information without your permission.

Hemophilia of North Carolina does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a chapter member of the Hemophilia Federation of America, a member agency of Community Health Charities, a member of the NC Center for Nonprofits.
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Jimmy the Greek Snyder, the Queen of Thailand, Bill Friday, Terry Sanford; and doctors Kenneth Brinkhous, Harold Roberts, Gil White, and Christine Johnson—all in service to the bleeding disorders community.

George was the first human to receive recombinant clotting factor, at the time called the “largest protein ever cloned.” This was in 1987 amidst the hoopla of a curious press with cameras, reporters, doctors and nurses in attendance. George’s very survival was in question. The story goes that when asked “how do you feel?” George replied with a distinctly rodent-like gesture of the upper lip. (The factor is produced using the proteins of Chinese hamsters.) Even if the story is apocryphal, George did not deny it.

George: you have enlightened, delighted and now saddened everyone you’ve touched. We will miss you so much.

George Dyer McCoy, 69, passed away on August 23, 2017 in Raleigh, NC, after fighting pancreatic cancer. George was born on November 28, 1947 to Sam and Anna McCoy, in Orlando, Florida. He was predeceased by his parents and an older brother, Richard. He is survived by his husband, Phillip R. Poovey; sisters Emily (Skip) Wilson and Carol Lockett; sisters-in-law Dianne McCoy Moore and Susan Lake (Bob) and brother-in-law Tom Poovey; nieces Debby Abbott, Kathy Bryan, Carolyn Nuscher, and Rebecca Smith (Joe); and nephews Jim McCoy (Dana), Edwin Lockett, and Michael Lockett (Cheryl), and many grand nieces and nephews.

George graduated with a B.A. from Eckerd College and earned an M.Ed. in Rehabilitation Counseling from UNC-Chapel Hill. He had a long and distinguished career with the State of NC as a rehabilitation counselor and program coordinator with the NC Division of Vocational Rehabilitation Services, Director of the Division of Deaf and Hard of Hearing, and Director of the Division of Vocational Rehabilitation Services.

Born with hemophilia, George was instrumental in establishing what would become the agency, Hemophilia of NC, back in the 1970s and was always an advocate for persons with disabilities. In 1987, he volunteered to be the first person in the world to receive a recombinant DNA clotting factor to control bleeding that was free of blood born viruses. When he retired from state service in 2005, he was awarded the Order of the Magnolia, from the Director of the Department of Human Resources and The Order of the Long Leaf Pine, from the Governor. In 2012, he traveled to Paris, France to attend the World Federation of Hemophilia and addressed the conference about his experience as a pioneer in the treatment of hemophilia. In August 2017, he was awarded the Dick James Lifetime Achievement Award from the National Hemophilia Foundation.

George will be greatly missed by his family, his many friends and former colleagues, and his neighbors. Thanks and appreciation to the nurses and staff at Transitions Life Care for the hospice services that allowed George to remain in his home. A Memorial Service and Celebration of Life will be held on November 12 at the Embassy Suites on Harrison Oaks Boulevard in Cary. Donations in his name may be made to: Hemophilia of NC, 260 Town Hall Dr., Suite A, Morrisville, NC 27560.

In order to honor George McCoy’s memory, HNC will be implementing a scholarship in his name. Donations received in memory of George will be designated toward this scholarship fund. Thank you for supporting this effort.
HAROLD R. ROBERTS, 1930-2017
Physician, Scientist, Teacher
Established the UNC Hemophilia Treatment Center

The bleeding disorders community in North Carolina – and the world beyond – has lost one of its true giants. Dr. Harold Roberts was known to many of us for his warmth, quiet humor, and fierce devotion to his patients.

He leaves us with an incredible list of accomplishments and contributions to hemophilia research, treatment and care. He was part of the team that pioneered powdered concentrates containing Factor VIII and Factor IX. He served as chair of the NHF Medical and Scientific Advisory Council (MASAC). And he established at UNC one of the country’s first Hemophilia Treatment Centers – one that now bears his name.

Dr. Roberts had a profound impact on our community, and will be greatly missed.

The following was originally sent from the International Society on Thrombosis and Haemostasis (ISTH).

Harold R. Roberts, First ISTH Executive Director, Dies at Age 87

We regret to report that Harold R. Roberts, M.D., the first Executive Director of the International Society on Thrombosis and Haemostasis (ISTH), died on Saturday, September 9. He was 87 years of age.

Roberts was a giant in the field of thrombosis and hemostasis and an instrumental guiding force and mentor within the ISTH. He was a charter member of the ISTH and served as Secretary General of the Scientific and Standardization Committee (SSC) from 1978 to 1988 before becoming the first Executive Director, a position he held until 1999. From 1999-2007, he served as Senior Associate Editor of the Society’s journal, where, together with Editor-in-Chief Pier Mannucci, he oversaw the founding and start-up of the Journal of Thrombosis and Hemostasis (JTH).

In recognition of his extraordinary accomplishments, the ISTH awarded Roberts with the Distinguished Career Award in 1983 and later, with the Robert P. Grant Medal, the highest honor of the ISTH, in 1995. Additionally, in 2006, the ISTH established the Harold R. Roberts Medal, a biennial award recognizing members for significant contributions to the SSC.

A native of Four Oaks, North Carolina, USA, Roberts earned his undergraduate and medical degrees from the University of North Carolina (UNC) at Chapel Hill. He was appointed to the faculty in 1961 and in 1967, he became Chief of the Division of Hematology. For 20 years, he served as Director of the UNC Center for Thrombosis and Hemostasis, which he founded in 1978. As a young scientist, Roberts worked with Kenneth Brinkhous, M.D., and in 1965, Roberts, Brinkhous and their colleagues developed the first highly purified concentrate of blood clotting factor VIII, which was later commercialized by Baxter-Hyland. In 1987, a UNC patient with hemophilia A became the first person in the world to be infused with recombinant factor VIII. At the bench, Roberts and colleagues revised the generally accepted theory of the day by showing that the clotting mechanism is localized at the site of bleeding.

Roberts received numerous honors for his achievements in hematology research, including the French International Prize for Research in Hemophilia, the Kenneth Brinkhous Award for Excellence in Clinical Research from the National Hemophilia Foundation and the American Society of Hematology’s Henry M. Stratton Medal. He received an honorary doctorate from the University of Lund. He was also the recipient of UNC Medical School’s Basic Science Teaching Award in 1965, and in 2000 he was presented the Medical Alumni Distinguished Faculty Award.

Roberts was known as an exceptional physician, and a perennial patient champion. He was a leader, mentor, counselor and scientific diplomat recognized internationally for his fairness, wisdom and devotion.

He is survived by two sons, Eric and John and two grandchildren, Carl and Alexandra. Roberts was preceded in death by his wife, Marilyn, earlier this year.

There is no further information available at this time.
Latin Union Learns Healthy Foods are Easy to Make!
June 17, 2017
Charlotte, NC

Who knew that healthy food could be easy to make, taste delicious, and be something the whole family could enjoy? On Saturday, June 17, twenty members of the Latin Union took part in a group cooking class at Flour Power: Kids Cooking Studio in Charlotte. Ready for a fun cooking experience, families sat around six tables and were provided the instructions and ingredients to make Parmesan Zucchini Chips and Healthy Veggie Pizza. First up was the zucchini chips. Kids and adults alike sliced up the zucchini into thin slices, then added a small amount of oil, breadcrumbs, and parmesan cheese. The zucchini chips were put into the oven while everyone started on to healthy personal veggie pizzas. Making the dough from scratch, adding pizza sauce, mozzarella cheese, and variety of vegetables, this was a healthier option to pepperoni or sausage pizzas made in a pizzeria. When everything came out of the oven, it smelled and tasted great!

Following the cooking class, Patricia Espinosa-Thomson presented a Shire HELLO TALK Food for Thought. Starting with an icebreaker, everyone introduced themselves, what country they are from, and had to remember where someone else was from. After going around several times, they learned about healthy food options, how many calories everyone should eat a day, and just how unhealthy fast food and sugary drinks such as soda and iced tea are. Everyone left the event feeling full and knowing a little more about how to eat healthy.

Mentoring Lunch ‘n Learn
June 3, 2017
Morrisville, NC

Mentors from Hemophilia of North Carolina’s (HNC) Mentoring Program gathered on Saturday, June 3 at the HNC Office in Morrisville to learn more about different resources and services to help and assist people beyond the support of HNC. Sally Wright, MSW, LCSW, and former social worker at the Hemophilia Treatment Center at UNC-Chapel Hill, facilitated a lively roundtable discussion. She talked about the importance of everyone doing their part when applying for services including researching, gathering necessary documents, and following up on their requests. Other topics of discussion included insurance and Medicaid, the mental healthcare system, Supplemental Security Income (SSI), and the ACCESS Program through Patient Services, Inc. (PSI) which helps people with chronic illnesses to navigate state and federal entitlement programs and provides legal support to those with bleeding disorders. While the adults were participating in the roundtable, the kids were having a blast watching a movie, doing crafts, and playing games.

The next mentoring Lunch ‘n Learn will take place this fall. If you are interested in learning more about the Mentoring Program, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or calling her at (919) 272-6000 or (800) 990-5557.

St. Jude Affiliate Clinic Takes Home the Cup
June 7, 2017
Charlotte, NC

For the second year in a row, St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital won the Hospital Cup for their fundraising efforts to support the 2017 HNC Family Festival & 5K Walk for Bleeding Disorders in Charlotte. The Hospital Cup is a competition between area hospitals that treat people with bleeding disorders to raise the most money for the HNC Family Festival & 5K Walk. As the winner, HNC awarded St. Jude Affiliate Clinic with a trophy and a catered lunch. Although it was a busy day at the clinic, everyone enjoyed the meal and was asking about next year’s Festival & Walk, which will take place on April 14, 2018 in uptown Charlotte.
Educational Dinners Around the State
June 20 & 21, 2017
Charlotte & Greenville, NC

Overcoming Challenges
On June 20, HNC members gathered at Maggiano’s in Charlotte for an educational dinner, *Overcoming Challenges*, presented by Daysi Fardales, Patient Affairs Liaison for Pfizer Hemophilia. The topic covered challenges that people with bleeding disorders face from school, work, relationships, doctors, and more. The room was buzzing with conversation as people shared their own experiences with challenges that they have faced in a variety of different situations. While no one was happy that they have had to go through these challenges, it was helpful and reassuring to know that others have faced some of the same difficulties, and resources were provided to get help including the Hemophilia of North Carolina (HNC) office, as well as national organizations the National Hemophilia Foundation (NHF) and the Hemophilia Federation of America (HFA).

Exploring Emotional Well-Being
On June 21, Daysi Fardales, Patient Affairs Liaison for Pfizer Hemophilia, presented the program *Exploring Emotional Well-Being*, to HNC members at The Seahorse Restaurant in Greenville. The presentation covered the importance of taking care of your emotional health and how emotional well-being can be a difficult to achieve when one is dealing with a chronic condition. Attendees engaged in an open conversation about the emotional impact a bleeding disorder can take on the person living with the condition, as well as caregivers and family members. Members shared stories about trips to the emergency room or engaging in other routine activities that became stressful because of a bleeding disorder. Not only did the presentation provide information about utilizing HNC or the local Hemophilia Treatment Center for resources, members in attendance shared with one another ways they have approached similar circumstances.

Following these presentations, dinners, and time to connect with new and old friends, participating families left with new resources and the dates for the next HNC events.
Once again, it was time to get the Carolina Crew, HNC and HSC teens, together for the annual Teen Retreat. The four-day adventure took place at Camp Canaan in Rock Hill, SC. Buses from both states came rolling into the camp with 30 excited teenagers that were ready to have some fun! The teen retreat offers an opportunity for our young adults to get together from across state lines, meet others, learn through entertaining activities, and simply be typical teenagers. Whether personally affected by a bleeding disorder, a child or sibling of someone with a bleeding disorder, or having another relative affected, the teen retreat is an inviting experience for all. They even get the option to bring a friend! Each year there is a nice mix of new and returning teens, providing an opportunity to catch up with some and spark new friendships with others.

HNC/HSC was fortunate to have GutMonkey come out again to facilitate the activities. GutMonkey has a way of incorporating learning into fun games like the dinosaur-arm-straw-challenge (you had to be there) and providing safe activities that involve a little risk like playing with mousetraps. Although no one got hurt, thanks to mature teens and great instructions, that element of perceived risk encourages our youth to realize their potential and not to let fear get in the way of growth. Thank you to Myles Ganley and Haelynne Barron for coming out, and to the entire team at GutMonkey for offering such creative, out-of-the box programs and being awesome role models to all.

The teens were quite busy during their stay with a chance to do the high ropes courses, swim, gaga ball, team up for a Rube Goldberg machine challenge, play laser tag, and a few other games. They also had time to relax and socialize, eat s’mores, make an ice cream sundae or two. They participated in an advocacy journaling session, which you can read about in the Our Young Voices supplement on page 16. It was an exciting four days, filled with many laughs and ah-ha moments. When it was time to get back on the buses and make the journey home, HNC/HSC staff was happy to already be hearing from teens about ideas for next year and their plans to return. A huge thank you to Camp Canaan and the staff, GutMonkey, sponsors, the teens who come with open hearts and minds each year, and to all of the volunteers who donate their time and energy to making this event such a success each year!

One organization that comes and the kids and I enjoy is called GutMonkey. They challenge the teens physically, mentally, and emotionally. The lessons are taught through various activities. Some of these activities include rope challenges, mental games that are very challenging, and group activities where discussion and games are designed to challenge you emotionally by discussing inner thoughts of have a bleeding disorder and their fears. Each year, I am honored to see these teens grow in just a few days. It is absolutely amazing to watch from day 1 to the day we finally leave. During this teen retreat, friendships are formed that are unbreakable. A friendship that lasts well beyond camp. A family. I am grateful to be a part of this family and in the lives of these awesome teens. This is a teen retreat that will push them beyond the teenage years, to propel them into adult years and taking along with them lessons and stories that will forever be a part of their lives. For me, a lifetime of gratitude and gratification.

From the Perspective of Arlette Whitaker, RN, and HNC Board Member:

Hemophilia of NC holds a yearly Teen retreat. The last three years I have volunteered as the camp nurse. Every year the children that attend this camp amaze me with their strength, gratitude, struggles, and victories. The camp have awesome guest speakers that come and talk about having a bleeding disorder, taking care of yourself, tackling challenges, and growth.
HNC NEWS & INFORMATION

HNC Men’s Retreat Moves East
July 28-30, 2017
Pine Knoll Shores, NC

The 2017 Men’s Retreat, a gathering of men who are living with a bleeding disorder or the father of someone with a bleeding disorder, was held at the Trinity Center in Pine Knoll Shores on the Crystal Coast of NC. The Men’s Retreat provides a unique opportunity for dads and blood brothers to connect and learn from each other.

The educational sessions included HFA’s Blood Brotherhood and Dads in Action Rap sessions on Friday, a full day program on Saturday by James Stroker of Inalex Communications called Your Miracle, Your Life that focused on how to “dance with adversity”, and a wrap up session on Sunday morning. Those in attendance also participated in several activities outside of the educational sessions including a campfire, cook-out, and heading out to the beach. Whether the activities were educational or just for fun, the men used their time to meet new people or catch up with old friends. If you are interested in participating in future events for men affected by bleeding disorders, please contact the HNC office for more information.

From the Perspective of Keith Fleming, HNC Member:
At the end of July, I had the opportunity to attend the Men’s Hemophilia Retreat at Pine Knoll Shores, NC. This was an enlightening experience for me.

Having a toddler with Hemophilia, the retreat gave me a great opportunity to dive in and learn much more about it. Having the chance to network, develop relationships and gain knowledge from so many men who have lived with hemophilia was truly valuable. It gave me a depth of perspective that is impossible to get from just talking to Doctors and asking Google.

Being able to understand the true impact of living with Hemophilia from some brave men really prepared me to deal with a severe potentially fatal illness only a few weeks later (which of course was complicated by my son having hemophilia). The experience has also provided some great insight on how to manage the long-term impacts of hemophilia as my son grows.

Overall the retreat was incredibly fun, educational and uplifting. I’m excited to attend more events in the future and get my son involved in this wonderfully tight knit community.
Over the weekend of August 12-13, approximately 60 people gathered at the Hilton Riverside in Wilmington, NC for the HNC Adult Retreat. The breakfast & registration on Saturday morning gave us some time to visit with vendors as well. Charlene Cowell, Executive Director, welcomed us all, and gave some instructions and details about hotel registration and parking, and the evening off-site plans. She then introduced our first speaker, Donnie Akers, lawyer, friend to all, representative of HFA (Hemophilia Federation of America), and self-described “person with Evolutionary Hemophilia” -- due to his long-time association with members of the bleeding disorders community. His talk was entitled “Be Prepared - Legal Tools for the Road Through Life.” Using examples from his own experiences, and those of some of his clients, he led us through discussions of medical powers of attorney, medical directives, access to medical information, our rights and responsibilities, encouraging each of us to think and plan carefully BEFORE we are in positions to need these items. He also talked about financial planning tools like “special needs trust” and “ABLE accounts” to be used to shelter assets so that individuals can remain eligible for public benefits. If I’m making it sound dry, trust me, it wasn’t! His engaging style encouraged questions and observations from the audience. Whenever you get a chance to hear him, please do.

We broke for lunch, and more time to talk to vendors and sponsors. The afternoon session, “Reconnecting the Mind and Body with Fitness”, sponsored by Aptevo, was presented by Cassie Starks. She was introduced by one of the Aptevo reps, with biographical details of a young woman with Hemophilia B (yes, women CAN have it), a collegiate championship pole vaulter, setting indoor & outdoor school records, and earning two NAIA All-American plaques. It is always inspirational to me to see people with bleeding disorders not being limited or defined by them. She first had us move our tables and chairs to form a large circle of people able to see and hear each other more clearly. Stress is generally present in all our lives, and can have a negative effect on our health and well-being. She offered us ideas for using our minds and bodies to reduce stress in our lives .... some as “simple” as deep breathing exercise or visualization, others accessible through several websites like www.daviddorianross.com for free TaijiFit classes. There were also hand-outs encouraging us to be active.

The late afternoon was given over to vendor visits, hotel registration, and free time to explore the area. I understand that a few people found treats at Kilwin’s (fudge and ice cream) a few blocks away. After dinner, several groups elected to participate in an off-site event at a break-out room experience. Although I spent my evening resting, then sitting outside near the riverfront pool and bar, watching the sunset, and talking to a couple of friends, I heard the next morning that the break-out sessions were fun, with mental rather than physical challenges.

Sunday morning, there was breakfast --- yes, we did do more than eat, but the food was delicious --- and time to check-out of the hotel. Our final session, “Get a Job - the ADA (Americans with Disabilities Act) and Your Rights and Benefits in Employment,” was once again led by Donnie Akers. As a retiree of more than ten years, I might have dismissed this topic as not relevant for me, but I’d have been wrong. Past experiences of family and friends made more sense,
HNC Adult Retreat  continued from previous page

and I learned things that should be helpful to people I know, now and in the future. For instance, being rejected for a job for which you meet all the listed requirements, strictly based on your diagnosis of hemophilia is absolutely forbidden by law. He emphasized insurance rights, privileges, and obligations as they now exist under the Affordable Care Act -- and encouraged us to be aware and vigilant in following possible changes to that law.

One other thing that Donnie encouraged all of us to do is to join Hemophilia Federation of America (HFA), the national nonprofit patient organization that assists and advocates for the bleeding disorders community. He reminded us that the next national symposium will be in Cleveland, OH, April 26-29, 2018. He pointed out that part of the gathering will be at the Rock & Roll Hall of Fame, and could only hint at potential guests.

HNC Takes Home Two Awards!  continued from page 1

four categories with the following chapters receiving recognition:

• Health Education Award: Hemophilia of North Carolina (HNC) & Hemophilia of South Carolina (HSC) for the Teen Retreat, aka, “Carolina Crew”

• Communications Award: HSC for their 2017 Communications Outreach Video

• Outreach Award: Hemophilia Foundation of Oregon for PEAK: Leading with a Clotting Connection

• Tami Wood-Lively Award: HNC for the HOPE Mentoring Program for Families with Young Children affected by bleeding disorders

HNC would like to acknowledge its board, staff, volunteers, participants, and the collaboration with our neighbors at HSC, as well as the Hemophilia Treatment Centers. It takes significant effort from all parties involved to make a program a success and is an honor to have these efforts recognized by others.
Back to School Dinner
August 17, 2017
Charlotte, NC

It was a packed room at the HOPE Educational Dinner hosted by HNC and Novo Nordisk at Upstream Restaurant. Sue Geraghty, RN, presented Community University—How to Communicate with Your Child’s School. Families streamed into the private room, eager to learn tips and tools about going back to school with a bleeding disorder. The conversation ranged from: communication with the teacher, school nurse, and other school personnel; to setting up a 504 meeting; individual health plans; where to turn for resources; and other needs that a child with a bleeding disorder may have in school. It was quite an impressive list of topics! Families talked with each other about their experiences, both positive and negative, and how they have overcome any obstacles that their child may have experienced. The children were kept entertained by a table full of crafts and Play-Doh. After everyone, adults and children alike, made some new friends, it was time to leave. Parents went home feeling a little more prepared to send their children off to the upcoming school year knowing that they now had some new tools to communicate with their child’s school.

Family Day Out: A Day in the Park
August 19, 2017
Clemmons, NC

The weather was perfect for the 2017 HNC Family Day Out event. About 60 people joined HNC for a picnic lunch, activities and networking, and then a visit to the Aquatic Center at Tanglewood Park in Clemmons, NC. Everyone arrived and had time to catch up, introduce themselves, and eat some lunch. Gillian Schultz, HNC Program Manager, and Charlene Cowell, Executive Director, spent some time talking about HNC Programs and highlighted the upcoming Family Festival & 5K Walk for Bleeding Disorders at Lake Crabtree Park in Morrisville on October 14. In the meantime, kids played games including ball toss, corn hole, and volleyball in the sand court that was next to the picnic shelter. They also were busy doing crafts and going to the playground that was just down the hill.

With it being a hot day, guests were happy to cool off at the Aquatic Center around the corner. Featuring a toddler splash pad, wading pool with fun water features, lap pool, diving boards, water slides, and a slow tubing river, it was the perfect way to cool off on a hot day.
El Programa Union Latina – Actualizacion

El Programa Union Latina del HNC ha tenido un sólido comienzo de año. Gracias a la ayuda de un voluntario de habla Hispánica, HNC ha logrado tomar contacto con mas miembros que los previos años, con el objetivo de conectar familias. Ha habido dos eventos desde Junio, el evento de cocina en Charlotte, que resultó ser un gran éxito para todos, del cual podrá leer más en esta edición de The Concentrate; y también el evento en Dave & Buster’s en Concord, donde la Union Latina celebro el Mes de la Herencia Hispana. Mas información respecto a este evento, en la edición de invierno del boletín. De la misma manera el Retiro Familiar celebrado del 15 al 17 de Septiembre en el Sea Trail Resort & Conference Center in Sunset Beach, tuvo una asistencia importante de miembros de la Union Latina.

El ultimo evento programado para la Union Latina para este año 2017, se llevara a cabo el 2 de Diciembre en Greenville, a continuación de la celebración de las fiestas del HNC. Esta es una magnifica oportunidad para reunirnos y celebrar las actividades realizadas durante el ano y para discutir como poder hacer crecer el programa el 2018.

La Union Latina es un programa diseñado por la HNC para apoyar y educar a los residentes latinos de North Carolina afectados por enfermedades hemorrágicas y también a sus familias. El programa es ofrecido en Espanol y es posible gracias a aportes de Shire. Para mayor información sobre el Programa Union Latina, visite el sitio HNC.

Celebrando nuestro dècimo aniversario con este año
Raleigh Family Festival & 5K Walk for Bleeding Disorders!

October 14, 2017
Morrisville, NC

Caminemos juntos apoyando la comunidad con desordenes hemorrágicos! La inscripción se ha abierto para participar en el Raleigh’s Family Festival & 5K Walk for Bleeding Disorders. Después del éxito obtenido en el evento de Charlotte, el pasado Abril, HNC esta enfocado en un aun mas grande evento, para crear conciencia, formar comunidad, crear activismo, y reunir fondos en el Lake Crabtree Park en Morrisville. Ojalá a estas alturas usted ya ha leído, visto y escuchado acerca del cambio de nombre de nuestro mas relevante evento. En lugar de Hemophilia Walk, ahora se le conocerá como el Family Festival & 5K Walk. Las expectativas son siempre reunir fondos, al mismo tiempo que disfrutar de un medio día de comidas, diversion, y actividades para participantes de todas las edades. Invite a sus amigos, familiares, colega y también a sus regalones “de cuatro patas” a ser parte de estas festividades y de los 5 K de caminata. Aproveche de saludar a algunos rostros conocidos de eventos pasados: Kevi McVerry de Performance DJ, nos deleitará nuevamente tocando las canciones que a todos nos gusta corear, y Jecoreography nos brindara entretenccion con sus estupendos movimientos.

Al igual que en el pasado, el éxito del Festival depende del apoyo de los participantes ya sea completando los 5 K, caminando en equipo, y recolectando donaciones para lograr las metas de la campana! Todos los fondos recolectados quedaran aqui en Carolina del Norte para dar soporte a los programas y servicios que HNC organiza para esta comunidad. Programas educacionales y de apoyo, iniciativas para activistas de pacientes, retiros y grupos de apoyo, y de mentores, asistencia en casos de emergencia, tarjetas de identificación de MedicAlert, el boletín, y mucho mas son posibles gracias a los esfuerzos de HNC Family’s Festivals'.

Estas son algunas ideas de que hacer para que este evento sea todo un suceso!
• Inscríbase para participar en el Festival & Walk de este año
• Promocione a su equipo e invite a otros a formar parte de el, o a donar por el equipo
• Organice sus propias actividades para recolectar dinero, en su casa, su lugar de trabajo, escuela, iglesia, o con sus vecinos
• Contacte a restaurantes locales y otros negocios para realizar eventos para reunir fondos
• Contacte a potenciales colaboradores, como negocios de compra y venta de vehiculos, oficinas medicas, bancos, compañias de seguro, o cualquier otro negocio que usted crea podría estar motivado. No tiene experiencia como pedir contribuciones? Estaremos felices de asistirlo. Esta es tambien otra forma de dar hacer conciencia colectiva!
• Necesita mas ideas para su campana? Contacte la oficina de HNC, o bien ingrese a nuestra pagina en internet para mas sugerencias.
Celebración de la Herencia Hispana y Diversion

Domingo, Septiembre 24
Concord, NC

Miembros de la Union Latina se reunieron el 24 de Septiembre en Dave & Buster’s, en Concord para celebrar una tarde de educación y diversión. Martha Borja, de la Hemophilia Federation of America (HFA) presentó un programa acerca de los derechos de contar con un intérprete que ayude a la comunicación entre el doctor, o la enfermera y el paciente. Los participantes disfrutaron de un delicioso almuerzo, la celebración del Mes de la Hispanidad, y la presentación. Luego a cada participante se le distribuyeron tarjetas para poder usar los juegos que ofrece Dave & Buster’s. Muchas gracias a Shire y a HFA que ayudaron a hacer este programa posible.

La Union Latina Aprende Acerca de Comidas Sanas
Faciles de Preparar!

17 de Junio, 2017
Charlotte, NC

Quién se habría imaginado que cocinar comidas sanas sería tan fácil, que son deliciosas y algo que toda la familia puede disfrutar?

El Sabado 17 de Junio, veinte miembros de la comunidad Union Latina participaron en una clase de cocina en Flour Power: Kid Cooking Studio en Charlotte. Listos para una entretenida experiencia de cocina, las familias se distribuyeron en seis mesas y se les proporcionaron las instrucciones y los ingredientes para cocinar chips de zapallitos a la parmesana y una sana pizza de vegetales. Tanto los niños como los adultos presentes, rebanaron los zapallitos en delgadas laminas, luego les agregaron una pequeña cantidad de aceite de oliva, pan rallado y queso parmesano. Pusieron los chips de zapallitos a cocinar en el horno. Mientras tanto, se pusieron manos a la obra a preparar pizzas individuales de vegetales. Primero prepararon la masa, luego le agregaron salsa de pizza, queso mozzarella y una variedad de vegetales, que es una alternativa mas sana que los pepperonis o embutidos, y que las pizza compradas en pizzerías. Las comedas oían y sabían deliciosas al sacarlas del horno!

Celebrando nuestro décimo aniversario...

Raleigh’s Family Festival & 5K Walk tiene su propia pagina en internet, la cual contiene valiosa información incluyendo direcciones de como inscribirse y preparar a su equipo, datos para reunir fondos, información para voluntarios, instrucciones en cómo llegar al lugar del evento, y cualquier otro detalle pertinente a este evento.

Cuando se esté inscribiendo, asegúrese de seleccionar la opción para crear una página para recolectar fondos, si es que su intención es recolectar donaciones o realizar algún tipo de evento de recolección de fondos para esta campana. Por favor tenga en consideración que hay algunos cambios en el proceso de inscripción y que esta vez estamos usando FirstGiving para organizar la inscripción y el proceso de recolección de fondos en la página de internet. Contacte la oficina de HNC al (800) 990-5557, o escribanos a festival@hemophilia-nc.org si es que tiene alguna pregunta o necesita información adicional acerca de este gran evento.
A Sisterhood is Strengthened
June 10, 2017
Winston-Salem, NC

On June 10, women affected by bleeding disorders and mothers of girls with bleeding disorders gathered together at the Graylyn International Conference Center for a day of sisterhood, bonding, education, and support. Women who helped form the SOAR group over 10 years ago attended, along with many women who are new to the SOAR Program. The 2017 SOAR Women’s Education Day featured a mix of social and educational opportunities. Beginning with a yoga session, the women had the opportunity to strengthen their bodies and minds through yoga poses and breathing exercises. Some of the women had practiced yoga in the past while others were brand new to the experience. Following yoga, the women heard from Kristen Prior from CSL Behring about managing stress, which seemed to be the perfect follow-up to yoga. The women then enjoyed a beautiful lunch in the Living Room Porch at the Manor House which overlooked the Graylyn property. After lunch there were SOAR roundtable discussions to help determine the strengths of the women of SOAR, and ways to improve programming, fundraising, and advocacy in the future. A discussion on intimacy was facilitated by Mary Ann Massolio of CSL Behring.

Following the day’s education was the Vineyard Challenge. The women were broken into teams. Each team had to come up with a name and marketing slogan and then with a recipe in hand, created their own signature Sangria. The Sangrias were evaluated by a panel of judges including a sommelier, chef, and the event coordinators from the Graylyn. The competition became very serious as they each tasted the different sangrias. In the end, the Women of SOAR team won the challenge but it was a very close competition! To end the day, an optional dinner was held where the women were able to chat and learn more about each other. There was truly not enough time for everyone and the ladies were excited to continue the event in the future and continue to grow the SOAR Program. Thank you to CSL Behring for making this event possible.

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.

Support • Outreach • Advocacy • Resources
SOAR’s Mission Statement: To improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.

An HNC Program for Girls and Women with Bleeding Disorders
SOAR Program Update

Being a woman or girl with a bleeding disorder can be very challenging at times. Between doctors who do not believe that women can have bleeding disorders, to the additional complications of a woman’s monthly cycle and childbirth, women have a lot to fight for. The SOAR Program works to bring down the barriers of care for women, while at the same time supporting and educating them so that each person can be their own advocate.

On September 14-15, a few women from the SOAR Program exhibited at the NCNA (North Carolina Nurse’s Association) Convention in Cary, NC. Over 400 RN’s attended the event which provided HNC the opportunity to share information with those who are first in meeting with a patient and integral in providing proper care.

The next SOAR Dinner will take place on October 17 in Charlotte and will focus on women with hemophilia, including carriers. Though the focus will be on hemophilia, any woman with a bleeding disorder is invited to attend. HNC will also be holding its SOAR Fundraiser this November in two locations, at Total Wine in Raleigh on November 11, and at Dish It Out Pottery Studio in Charlotte on November 18. More information about both events is available on the HNC website.

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 affected 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.
Ideas about Advocacy from the Teen Retreat

HNC Teens discuss “What is Advocacy?” at the Teen Retreat in an exercise to get them thinking about advocacy and how they can get involved in advocacy efforts. Here’s what they had to say:

Advocacy to me is to speak up and when you speak up you can change the world.
~WR

What is advocacy? That my medication is important to my life.
~WC

I don’t advocate because I’m afraid to.
~LS

Advocacy: Doing what you think is right; standing up for what you believe in.
~MM

We can advocate without truly realizing the actions we’ve taken are a form of activism. However, well thought-out and compassionate advocates are more influential and impactful.
~LG

I think that people should think about what you believe and respect what other people believe.
~BM

I think this (advocacy) means that you/I can stand and speak up about what we/I believe in.
~NC

What does advocacy mean to you?

For more pictures of the 2017 HNC/HSC Teen Retreat, visit the HNC Facebook page
HNC was pleased to be invited to St. Stephen Missionary Baptist Church to participate in their annual Family and Friends Day. Charlene Cowell, HNC Executive Director, and Karyn Davis, HNC Manager of Operations, had the opportunity to join the church at their worship service and festival and get to know more about this inspiring group of people who come out to support HNC as Team Jaden’s Jewels and Jaden’s Gents. Since 2012, this team has been fundraising for the Raleigh Festival and Walk, raising more than $25,000 through the years. In addition, with the support and commitment from Erica Cook, Gwen Stewart, and the entire St. Stephen’s family, their participation continues to promote awareness about bleeding disorders throughout the greater community.

As part of this event, HNC was welcomed to the church to enjoy the choir, drama, and dance ministries as well as an inspirational message from Pastor James Cook. When the service completed, church members were offered lunch with delicious homemade desserts. There was a bounce-house for kids to enjoy, a back to school tent that provided backpacks filled with school essentials for students starting a new school year, and a Health & Fitness Tent where church members could get their blood pressure checked and learn more about HNC, bleeding disorders, and the upcoming HNC Family Festival & 5K Walk for Bleeding Disorders. HNC provided all the fixings for a trail mix bar for church members who stopped by to ask questions or register for the Festival in October.

HNC sincerely thanks everyone who is involved in the success of Jaden’s Jewels and Jaden’s Gents team. They have been one of the top fundraising teams in Raleigh since they began fundraising in 2012 and continue to be a role model to other teams. The dedication and determination displayed by team, committee, and church members is inspiring. A special thank you to Gwen Stewart and to the Cook family for always being so organized and creative in their fund- and awareness raising efforts!!

St. Stephen’s Family and Friends Day
August 20, 2017
Winston-Salem, NC

A young member of St. Stephen’s with her HNC Piggy Bank

St. Stephen member enjoying the Trail Mix Bar

因子替代反映的保护

对于血友病患者，因子替代治疗暂时补充所缺失的成分。1 通过长期的疗效记录和证明的结果，因子替代治疗可以与您体内的自然凝血过程形成一个合适的血凝块。2,3

Brought to you by Shire，专注于超过60年的血友病的发现和治疗。

Stay empowered by the possibilities.

Shire

There was something for everyone at the NHF’s 69th Annual Meeting this year. With educational sessions for every sector of the community and a conference theme of Exploring the New Frontier, it was difficult for attendees to decide which session to attend among all the offerings. Special tracks were available for Chapter Staff, Families, Newly Diagnosed, Adult Men, VWD, Women with Bleeding Disorders, Spouses and Partners, Teens & Young Adults, Spanish Speaking Members, Physicians, Physical Therapists, Nurses, and Social Workers. Childcare was also available for children under 12 years old.

The meeting was a wonderful opportunity for anyone in the community to learn more about bleeding disorders from the basics of each type of bleeding disorder, to new treatments available now, and what’s on the horizon with advancements begin made in the area of genetics. There were also many sessions geared toward helping members understand how to better manage living with a bleeding disorder or being the caregiver of a person with a bleeding disorder. It was chance to learn from the experts while also connecting and learning with community members from around the country.

HNC will notify members of the date of next year’s NHF Annual Meeting (scheduled to be held in Florida) when that information becomes available. Members are encouraged to apply for travel scholarships to attend these meetings, so they can bring back information that would benefit fellow members in NC.

From the Perspective of Cheri Clark, HNC Member:
I had the privilege of attending NHF’s 69th Annual Meeting in Chicago, Illinois, August 24-26, 2017. The long weekend was filled with numerous informational sessions on topics ranging from bleeding-related issues to a variety of others including addiction, art therapy, and even tai chi. The diversity of offerings provided something for everybody, whether dealing with vWD, hemophilia, or another bleeding disorder.

I was personally thrilled to see the many sessions related to von Willebrand Disease, since I have type 1 vWD. Each time I attend a conference, I learn something new. I was particularly excited to hear about a new assay launched by BloodCenter of Wisconsin called VWF GPIIbM that more accurately measures von Willebrand factor activity. This will help physicians overcome some of the diagnostic challenges related to vWD.

Moved by her son’s story at one of our annual meetings, I was again honored to see Jeanne White-Ginder speak about not only Ryan, but the National AIDS Memorial Grove in San Francisco. Her passion for this community is very apparent. I am blessed to have witnessed how far we have come since her son was diagnosed with AIDS so many years ago.

It was my pleasure to be present when HNC received awards, especially the award for George McCoy. I did not know George well, but have heard so many wonderful things about him from several HNC members. This prompted me to read more about his story online. What a deserving person; this community lost a great man when they lost him.

The weekend concluded with a reception at Chicago’s Field Museum, which included dinner, drinks, dancing, and the opportunity to get to know one another better. I am incredibly grateful to all of you and to Charlene, Karyn, and Gillian for their tireless efforts in making our chapter the best in the country! Here’s to another weekend with the bleeding disorders community, my extended family!

Family Retreat
Sunset Beach, NC
September 15-17, 2017
The HNC Family Retreat took place on September 15-17, 2017 at the Sea Trail Resort & Conference Center in Sunset Beach, NC. The newsletter was in production during this time but look for a recap of this great event in the winter edition of The Concentrate.
Let’s walk together in support of the bleeding disorders community! Registration is open for the Raleigh Family Festival & 5K Walk for Bleeding Disorders. After a very successful event in Charlotte this past April, HNC is gearing up for an even bigger day of raising awareness, community building, advocacy, and fundraising at Lake Crabtree Park in Morrisville. Hopefully by now you have read, seen, and heard about the name change for our largest event. Instead of the Hemophilia Walk, you will now hear about the Family Festival & 5K Walk. You can expect the same great fundraising event as before, filled with a half day of food, fun, and activities for people of all ages. Bring your friends, family, co-workers, and 4-legged friends for a great day of fun, festivities, and 5K walk. Say hello to some familiar faces from past events: Kevin McVerry from Performance DJ will join us again playing music to get the crowd ready and Jecoreiography will be entertaining us with their great dance moves.

As in the past, the Festival’s success depends on the support of individual walkers, walk teams, and sponsors in order to reach our fundraising goals! All money raised stays right here in North Carolina to support programs and services HNC provides to the community. Educational and support programs, patient advocacy initiatives, retreats and peer support groups, the mentoring program, emergency assistance, MedicAlert IDs, the newsletter, and so much more are made possible because of the HNC Family Festivals’ fundraising efforts.

Here’s what YOU can do to make this event a success!

• Register to participate in this year’s Festival & Walk.

• Promote your walk team and ask others to join your team or donate.

• Set up your own fundraising event at your home, office, school, place of worship, or neighborhood.

• Contact local restaurants and businesses about hosting a fundraising event.

• Contact potential supporters like car dealerships, doctor’s offices, banks, insurance companies, or any business that you think could be interested. Not sure about asking? We’re happy to assist. This is also a great awareness raiser!

• Need some fundraising ideas? Contact the HNC office or look on our website for suggestions.

The HNC Family Festival & 5K Walk page on the HNC website has a lot of valuable information including directions on how to register and set up your team, fundraising tips, volunteer information, directions, and anything else you might want to know about the event. When registering, be sure you select the option to create a fundraising page if you plan to collect any donations or do any type of fundraising. Please note there are some changes to the registration process as we are now using FirstGiving to host our registration and fundraising webpages. 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.

Celebrating our 10th Anniversary with this year’s Raleigh Family Festival & 5K Walk for Bleeding Disorders!

October 14, 2017
Morrisville, NC
**Women with Hemophilia: An Educational Dinner**

**October 17, 2017**  
**Charlotte, NC**

Are you a woman with a bleeding disorder? A mom of a girl with a bleeding disorder? A woman who is a carrier of hemophilia? We invite women and girls age 12 and older, for a SOAR Educational Dinner and presentation, *Women and Girls with Hemophilia*, on October 17 at Firebirds Wood Fired Grill in Charlotte (Southpark). Learn how women inherit hemophilia, what it means to be a carrier of the hemophilia gene, and the effects of hemophilia on women and girls.

Though the presentation will focus on women and girls with hemophilia, we invite any woman with a bleeding disorder or mom of a daughter with a bleeding disorder to attend this educational session. You can find more information on the HNC website or email SOAR@hemophilia-nc.org.

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**Blood Brotherhood Retreat**

**October 20-22, 2017**  
**Blowing Rock, NC**

Are you an adult male (18+) with a bleeding disorder? Are you looking to connect with others who also have a bleeding disorder? Join the HNC Blood Brotherhood Retreat from October 20-22 at Blowing Rock Retreat Center in Blowing Rock, NC.

The weekend will feature a casual social agenda, with time to get to know each other, make connections, and catch-up with old friends. Some of the events planned include evening campfires, lots of eating, and an optional offsite activity.

The Blowing Rock Retreat Center is a beautiful facility in the heart of Blowing Rock, NC. All meeting space is wheelchair accessible and most sleeping rooms will be on the first floor. All meals and accommodations will be provided. For more information, or to register please visit the HNC website or call the HNC office at (800) 990-5557.

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**HNC Community Yard Sale**

**October 21, 2017, 8am – 12noon**  
**Morrisville, NC**

Hemophilia of North Carolina (HNC) is hosting its annual Yard Sale event, so clean out your closets, attic or basement, and bring your stuff to Morrisville! Or, if you can’t make it to Morrisville, host a yard sale of your own on the same day and donate the proceeds to HNC! The HNC Community Yard Sale will take place from 8am to 12 noon at the HNC office in Morrisville.

HNC staff and volunteers would love to have you donate items or come by the HNC office to help out the day before or day of the sale.

Suggested items for donation include:

- Small furniture in good condition
- Small working appliances
- Dishware/ cookware
- Electronics
- Video games
- Books, games, bikes, and toys
- Clothes
- Baby stuff
- Artwork
- Home décor
- Shoes
- Music
- Jewelry, purses, accessories
- Holiday decorations

Contact HNC by phone at (800) 990-5557 or email info@hemophilia-nc.org to coordinate with staff about volunteering, dropping off your items on or before Friday, October 20, or about hosting your own yard sale in another part of the state. HNC staff will work with you and advertise your yard sale as part of our statewide event.
Gather with Friends in Greenville at the 2017 Holiday Celebration
December 2, 2017
Greenville, NC

HNC will hold its annual Holiday Celebration in Greenville this year, so come out, bring your loved ones, and enjoy some festivities with the entire HNC family! This year’s HNC Holiday Celebration will be held on Saturday, December 2, at the Hilton Greenville. Whatever your age, you will surely enjoy this gathering of the community where members will get to enjoy food, fun, a motivational presentation, and a visit from Santa with a gift for all the children in attendance. This is an excellent opportunity to come together as a community to celebrate the end of a great year.

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

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.

Working for you in the Mid Atlantic—From the Virginia shoreline to the Delaware River
Name: Linda Pollhammer
Home state: Maryland
Fun fact: Funny, feel-good movies are my favorite. Nothing sad—I love to laugh!
Family traditions: Music is a HUGE part of my family’s life. There’s always music playing in the house.

What motivates you as a liaison? As a nurse educator, I’ve had experience with hemophilia since 2010. Working with the community and helping them with their challenges is where I’m in my element.

To get in touch with Linda, call Pfizer Hemophilia Connect 1.844.989.HEMO(4366)

“What getting involved in this community is rewarding because our community is outstanding.”
—Linda Pollhammer
“Hearts for Hemophilia” Casino Night moves to Durham!

January 27, 2018
Durham, NC

The 11th Annual “Hearts for Hemophilia” Casino Night will take place on January 28, 2018, so mark your calendar today! The event is moving to the Durham Convention Center this year and should prove to be an exciting night for all who attend. Wonderful food, silent and live auctions, casino games, and music are all in the cards for the evening, so please join in the fun at this festive night out all for a great cause. If you know of a person or business that might want to support the event through an auction or raffle item donation or by becoming an event sponsor, HNC is always looking for new partnerships! To find out more information about the upcoming Casino Night, please call the HNC office.

2018 HNC Annual Meeting: Save the Date

March 10, 2018
Winston-Salem

Hemophilia of North Carolina (HNC) will host its 45th Annual Meeting of the Membership on March 10, 2018, at the Embassy Suites in Winston-Salem, NC.

Save the date for this full day of education, community, and supportive programming. This is HNC’s largest one-day educational opportunity with programs available for members of all ages, backgrounds, types of bleeding disorder, and relationships within the community. It will provide attendees with an opportunity to hear from expert speakers, knowledgeable medical professionals, and fellow community members in order to learn more about important news and information on the topic of bleeding disorders.

There is something for everyone at the HNC Annual Meeting, so please be on the lookout for more information coming soon on session topics and speakers as well as how to register.
From time to time, we hear from HNC members who do not know what the HOPE Program is or who it is geared towards. The HNC HOPE Program is intended to support families with younger children who have a bleeding disorder. If you are new to HNC or have a child age 12 or under with a bleeding disorder, HOPE is for you. As an HNC member with a child in this age range, you are automatically a part of the HOPE Program, and we encourage you to take advantage of the different events throughout the year aimed at supporting you and your family.

Each year, we host a number of educational dinners with a focus on education for families with younger children. In 2018 and beyond, we are also looking to expand and host regional groups that target areas of the state that we may not always reach with the dinners. If you are interested in regional group near you, please contact us and let us know.

Another part of the HOPE Program is the Mentoring Program. This was started due to a request from a number of HNC members who were interested in a more substantial and intense support program. We have several mentors, all who are caregivers of someone with a bleeding disorder, who are trained and looking forward to working with other families in the community. Whether you are a parent, grandparent, adoptive or foster parent, the caregiver of a baby or child recently diagnosed with a bleeding disorder; if you are going through a hard time with your child’s bleeding disorder, or just need that person who understands and can help you by providing a shoulder to lean on and a wealth of resources, the Mentoring Program is for you.

For more information about the HOPE Program, if you have ideas for events or are looking for an event near you, or would like more information about the Mentoring Program, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org, by calling HNC office at (800) 990-5557, or by calling Gillian directly at (919) 272-6000. You may also check the HNC webpage, Facebook page, and your email for updates on upcoming programs and events.
George McCoy Receives Lifetime Achievement Award
August 26, 2017
Chicago, IL

It was a bittersweet moment at the National Hemophilia Foundation (NHF) Annual Meeting Award Ceremony to have George McCoy honored for his contributions to the bleeding disorders community just days after his passing. This well-deserved award was a poignant reminder of how one person’s journey through life can impact so many others and in such a positive way. You can read about George’s life and accomplishments on pages 1 and 3 of this newsletter. His contributions span across the many issues that impact this community which George faced head on with the right balance of honesty, serious-mindedness and also humor.

The Lifetime Achievement Award, named in honor of Dick James, recognizes an individual who has dedicated his/her life to the bleeding disorders community in order to improve the lives of those affected. This person has contributed his or her time and energy on a national/international scale to advance research, care and advocacy, and develop new leadership that will lead this organization into the future. Dick James (1951-1993), who had hemophilia and AIDS, was an advocate and leader on behalf of people with bleeding disorders and HIV.

With that in mind, the NHF could not have chosen a more deserving recipient of this award.

If you would like to view a video of the award ceremony, visit the HNC YouTube Channel. You can either type this link into your browser (https://youtu.be/5IweTleQHRY) or go to YouTube.com and search Hemophilia of North Carolina.

Latin Union Program Update

The HNC Latin Union Program has been going strong this year. Thanks to the help of a Spanish-speaking volunteer, HNC has been able to personally reach out more members than in past years, in order to connect families with one another. There have had two events since June, the cooking event in Charlotte which was a big hit for everyone that you can read more about in this edition of The Concentrate, and the event at Dave & Buster’s in Concord as Latin Union members celebrated Hispanic Heritage Month. You can read more about the day at Dave & Buster’s in the winter edition of the newsletter. The Family Retreat on September 15-17 at Sea Trail Resort & Conference Center in Sunset Beach, NC, also had a nice turn out of Latin Union members.

The final Latin Union event for 2017 will take place on December 2 in Greenville following the HNC Holiday Celebration. This is a wonderful opportunity to gather together to mark the end of another great year for the Latin Union Program and talk about how the program can continue to grow in 2018.

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 to meet the unique needs of the Latino population living with a bleeding disorder. Visit the HNC website for more information on the Latin Union program.

Blood Brotherhood Program Update

The Blood Brotherhood Program here in North Carolina continues to thrive and any adult male (18+) living with a bleeding disorder is encouraged to get involved in this wonderful program. Through the Hemophilia Federation of America (HFA), the Blood Brotherhood Program connects men from across the country via a private online forum (visit www.hemophiliafed.org to register).

In addition to the online forum Hemophilia of North Carolina has hosted a series of educational events throughout 2017 including: sessions on: Kinesiology taping, using Music Therapy for pain management, partnering with the HOPE Program for families, the Men’s Retreat in conjunction with dads of someone with a bleeding disorder, and cardiovascular concerns as people age with a bleeding disorder.

The Blood Brotherhood program in NC will close out its 2017 programming with the HNC Blood Brotherhood Retreat in Blowing Rock, NC from October 20-22. The social retreat offers a unique opportunity for guys to connect, create friendships, and share experiences with guys who can relate.

As always, HNC appreciates the generosity of HFA and the National Program Sponsors for Blood Brotherhood – CDC Collaborative Partners; Accredo; Shire; CVS Specialty; and Genentech.
My Life, Our Future Research Repository Enrollment to end December 31, 2017

My Life, Our Future (MLOF) is a nationwide campaign that offers free genotyping for people with hemophilia A and B, as well as for potential and confirmed carriers. Participants from across the country have contributed to create the world’s largest genetic hemophilia repository. The My Life, Our Future Research Repository is a collection of samples and data. Scientists have the opportunity to apply for access to the MLOF research repository to assist with their research.

Please note that genotyping and participation in the repository require that a blood sample be collected at a participating Hemophilia Treatment Center (HTC).

Participation in the repository will come to a close as of December 31, 2017; so contact your local HTC as soon as possible to schedule an appointment to participate. The following HTCs in North Carolina are participating:

- East Carolina University
- University of North Carolina Chapel Hill
- Wake Forest University School of Medicine

Contact your local Hemophilia Treatment Center to schedule an appointment and participate in the free genotyping campaign.

Visit IXINITY.com

ON THE NATIONAL & LEGISLATIVE FRONT

National AIDS Memorial Grove Honors Hemophilia Community

On September 16, 2017, the hemophilia memorial at the National AIDS Memorial Grove will be dedicated in honor of the lives lost to HIV/AIDS in the hemophilia community. This will be the first permanent memorial erected to tragedy wrought on the hemophilia community by HIV/AIDS.

During the AIDS epidemic, over 50% of those with hemophilia in the United States died from the disease as a result of the contaminated blood supply. The memorial will serve as a tribute to the courageous efforts of the hemophilia community who worked to ensure a safe blood supply for all and will continue to do so in order to make certain this kind of tragedy will never happen again.

This memorial will finally give the hemophilia community a place where its grief can find its solace and a home; where family members can come to remember their loved ones; and where visitors from across the US and around the world can learn about the devastation faced by the hemophilia community.

The Hemophilia Memorial will be supported by contributions only from individuals and advocacy organizations. For more information about how to donate or to have a loved one’s name engraved at the memorial, visit www.aidsmemorial.org/support/hemophilia

HNC Advocacy Update

You may have noticed an increased number of Action Alerts in recent months from our Advocacy Committee. These alerts are sent to provide you with news from our national organizations about health reform legislation that will profoundly affect our community. HNC makes it a priority to advocate for people with bleeding disorders here in NC and nationally, and urges all members to answer these calls to action. Another way for members to participate in advocacy efforts is by contacting HNC when you hear something or have an experience you feel needs to be brought to the attention of community members or local or national legislators.

Through these efforts, HNC can best represent the bleeding disorders community of North Carolina and members can better advocate for themselves and all people with bleeding disorders. Since bleeding disorders are rare, every voice matters.

The Advocacy Committee will continue to alert members when action is required to reach out to your government officials on behalf of the bleeding disorders community about pending legislation or proposed changes to existing policies. Be on the lookout for more emails as issues arise.

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
2017 Calendar of Events Highlights

October 14, 2017  HNC Family Festival & 5K Walk for Bleeding Disorders – Morrisville, NC
October 17, 2017  HNC SOAR Dinner – Charlotte, NC
October 20-22, 2017  Blood Brotherhood Retreat – Blowing Rock, NC
October 21, 2017  HNC Yard Sale Fundraiser – HNC Office, Morrisville, NC
November 4, 2017  HNC Cyclebar Spinning Fundraiser – Charlotte, NC
November 11, 2017  HNC SOAR Fundraiser – Raleigh, NC
November 18, 2017  HNC SOAR Fundraiser – Charlotte, NC
December 2, 2017  HNC Holiday Celebration – Greenville, NC
December 2, 2017  Latin Union post-Holiday Event – Greenville, NC
January 27, 2018  Hearts for Hemophilia Casino Night – Durham, NC
March 9-10, 2018  HNC Annual Meeting, Winston-Salem, NC
April 14, 2018  HNC Family Festival & 5K Walk for Bleeding Disorders – Charlotte, NC

Bioverativ is committed to making a meaningful impact in the lives of people with hemophilia and other rare blood disorders by:

• Striving for progress when and where people need it most
• Advancing innovative programs to address serious unmet needs
• Challenging the status quo at every step with focus, urgency, and integrity
• Carrying on Biogen’s hemophilia treatments with a continued focus on quality, safety, manufacturing, and product accessibility

Visit Bioverativ.com to find out more

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Saturday, October 14, 2017
Lake Crabtree County Park
1400 Aviation Parkway
Morrisville, NC

Check-ins begin at 9:00am
Walks begin at 10:00am

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

Come out and celebrate Hemophilia of North Carolina’s (HNC) 10th annual Family Festival and 5K Walk, a fundraiser 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:
Charlene Cowell, HNC Executive Director
at festival@hemophilia-nc.org or call (800) 990-5557.

save the date
START YOUR WALK TEAM TODAY!