

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2016

## HNC Looking Ahead Through 2016

HNC was very busy during the first Quarter of 2016. If you were not able to attend the variety of events that have taken place so far this year, you can read about them in this issue of *The Concentrate*. Without the support from HNC members, these programs and events could not be successful. HNC would like to take a moment to thank all the community members who participated to make these events positive and memorable experiences for everyone present. Attending and participating in an HNC event is a great way to get involved, learn important information about bleeding disorders and meet other fellow members!

Whether or not you have been able to participate in an HNC program or event in the past, please take one minute to complete this brief two-question survey and let HNC know why you have or have not attended any HNC events yet. Follow this link, [www.tinyurl.com/HNCsurvey](http://www.tinyurl.com/HNCsurvey), or scan this QR Code to access the survey.



*Continued on page 16*



## Don't Miss Out on the Largest Educational Opportunity in NC

HNC 43rd Annual Meeting  
May 14, 2016  
Sheraton Greensboro Hotel

*Did you know that the Hemophilia of North Carolina (HNC) Annual Meeting is the largest educational opportunity within NC to learn about bleeding disorders? The Annual Meeting has been taking place for 42 years, and we look forward to making our 43rd larger than ever with your help and support! As always, this is a great opportunity for you to network with fellow members and to hear from the experts on topics relevant to you.*



Do you know the history of our community? It is imperative that we are all knowledgeable about our past. Otherwise, we cannot fully appreciate all of the meaningful work that individuals who came before us did in order to create the bright future that has become our reality. **Jeanne White-Ginder** is the mother of one of these individuals, Ryan White; and we are honored to have her join us as a guest speaker for this year's HNC Annual Meeting. Our history is substantial

*Continued on page 17*

## Save The Date

**Latin Union Event**  
N.C. Zoo, Asheville, NC  
April 9, 2016

**Charlotte Walk**  
Charlotte, NC  
April 16, 2016

**Blood Brotherhood  
Movie Night**  
Charlotte, NC  
April 16, 2016

**World Hemophilia Day**  
Charlotte, NC  
April 17, 2016

**HNC Annual Meeting**  
Greensboro, NC  
May 14, 2016

**HNC Legislative Day**  
Raleigh, NC  
June 14, 2016

**HNC Men's Retreat**  
Blowing Rock, NC  
June 10-12, 2016

**Latin Union Event**  
Charlotte, NC  
June 18, 2016

**HNC/HSC Teen Retreat**  
Camp Canaan, Rock Hill, SC  
July 7-10, 2016

**NHF Annual Meeting**  
Orlando, FL  
July 21-23, 2016

**WFH Congress**  
Orlando, FL  
July 24-28, 2016



*Hemophilia of  
North Carolina*

260 Town Hall Dr., Suite A  
Morrisville, NC 27560  
(800) 990-5557  
[info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)  
[www.hemophilia-nc.org](http://www.hemophilia-nc.org)

## 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 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

## About This Publication

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

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

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

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

## Hemophilia Treatment Centers

### East Carolina University Brody School of Medicine

600 Moyer Boulevard  
Pediatric Hematology/Oncology  
MA Suite 333  
Greenville, NC 27834  
Phone: (252) 744-4676  
Fax: (252) 744-8199

### University of North Carolina Hemophilia and Thrombosis Center

170 Manning Drive  
3rd Floor Physicians Office Building  
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

## 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

### St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Hematology & Oncology Clinic

301 Hawthorne Lane, Suite 100  
Charlotte, NC 28204  
Phone: (704) 384-1900

## 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

## VISION STATEMENT

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

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



# Stay Connected with HNC in 2016

Do you use Facebook? Do you Tweet? Hemophilia of North Carolina does too!

Take a moment to “like” Hemophilia of North Carolina on Facebook and “follow” @HemophiliaNC on Twitter to keep up with news and events at HNC and other efforts supporting the bleeding disorders community. You’ll also find us on LinkedIn and inspiring videos on our YouTube channel – just search ‘Hemophilia of North Carolina’.

Don’t worry! We’re not replacing HNC’s traditional communication resources, just adding more options for our members to stay in the know. Members can still count on getting complete and detailed information through our routine methods of communication including the website ([www.hemophilia-nc.org](http://www.hemophilia-nc.org)), regular mailings, emails, and *The Concentrate* to stay up-to-date.



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[www.hemophiliafirst.com](http://www.hemophiliafirst.com)

## Mail Containing Information on Products and Services (Third Party Mailings)



### Important Update for HNC Members!

We know that most members of our community are interested in learning about products and services that may be available to them. As a part of our mission to provide education to our community we will occasionally send you mail on behalf of pharmaceutical companies, home health care agencies, or specialty pharmacies. In each of these third-party mailings, there will be an insert stating HNC’s policy:

Hemophilia of North Carolina (HNC) is providing this information as a service to our membership. We are not the sponsors, nor do we endorse, any of the events or products described in this enclosure. HNC always recommends that you consult your physician or local treatment center before pursuing any course of treatment. This mailing was addressed by HNC staff; your name and address have not been given to any third party.

If you prefer not to receive third-party mailings from HNC, please send us email at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org) or call 800-990-5557 and ask to be removed from this mailing list. (Doing so will exclude you from third-party mailings only, not from other HNC mailings).

# Strengthening the HNC Board of Directors

The ongoing challenge for any nonprofit organization is building and sustaining a high-functioning board of directors. To help ensure the long-term sustainability of Hemophilia of North Carolina (HNC), the Board of Directors has made the decision and commitment to be more deliberate and focused in the ongoing process of building our board.

At this time HNC is looking for board members with these talents and/or individualities:

- Individuals who represent the diverse demographics of our community
- Fundraising
- Accounting/Finance
- Public Relations/Communications

The board and volunteer positions are open to both HNC members and qualified individuals outside of our affected community. Persons who could be potential candidates include: professionals in your local sphere of influence, friends, alumnus from local colleges and

universities, retired individuals who worked in related industries, and NC small business owners in related industries.

**CALL TO ACTION:** If you know of anyone that might be a good candidate for our board of directors or other volunteer roles, please contact Charlene Cowell by phone (800-990-5557) or email ([info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)).

The HNC Board has been working on this initiative with the help of Executive Service Corps (ESC). ESC is nonprofit organization that provides affordable consulting to other nonprofits to help them achieve their missions.



## *Interesting Facts about Bleeding Disorders Today and throughout History*

- It takes an average of 16 years for a woman to receive a proper diagnosis of von Willebrand disease. Misdiagnosis is often a problem, with thousands of women worldwide undergoing unnecessary hysterectomies each year.
- Hemophilia is sometimes referred to as “the royal disease” because several members of noble families in Europe were affected by it and because Queen Victoria, Queen of England from 1837 to 1901, was a carrier.
- Many reputable scientists of the past claimed early success in treating hemophilia with unusual substances including egg whites, peanut flour and snake venom!
- There is no cure for hemophilia yet but gene therapy remains an exciting possibility and holds out the prospect of a partial or complete cure for hemophilia.
- Nurses are key members of the bleeding disorder treatment team as they provide the link between the patient and the other medical providers.
- Von Willebrand Disease is the most common bleeding disorder, affecting as many as 1 in 100 people.
- The worldwide incidence of hemophilia is estimated at more than 400,000 people. Approximately 70% of people around the world do not have access to treatment.
- According to the CDC, mortality rates are 40% lower in people who use HTCs than in those who do not.
- The most common symptom of hemophilia is bleeding into muscles and joints. Untreated, this leads to severe crippling.
- Hemophilia is a genetic disorder; however, in about 1 in 3 cases, there is no history in the family. The cause is a new genetic mutation. Thus hemophilia can affect any family.
- Hemophilia B (Factor 9 deficiency) is also known as the Christmas Disease, named after Steven Christmas, a Canadian who in 1952 was the first person to be diagnosed with this distinct form of hemophilia.
- During the 1970s, pools of donors for plasma products ranged from 15,000 to 60,000 people. Since 1986, no cases of HIV transmission from factor concentrates have occurred.
- In the 1950s the average life expectancy for patients with hemophilia was 10.2 years.

## HNC on the Road Again

As part of our mission at HNC, our goal is to bring educational opportunities to the community. In February and March, we held four educational dinners across the state, two in Charlotte and two in Raleigh-Durham. We were glad to have so many smiling faces in attendance and taking an interest in these learning opportunities.



In February, HNC went to Charlotte and partnered with Baxalta for a dinner and program entitled “Sharing Your Story”. This event drew a great crowd of people who are interested in learning how to tell people their own story, whether it is for the purpose of advocacy, fundraising, or spreading general awareness.

In March, HNC was in Durham and partnered again with Baxalta for another dinner and program focused on Legislative Advocacy Training. This always-popular presentation brought out dozens of members to learn about speaking to their elected representative while helping them prepare for when we go to our Legislative Days in Raleigh this June. The program was a mix of Legislative 101 and discussion of current challenges we are advocating for, both nationally and locally.

HNC partnered with Biogen for two educational dinners in March, one in Charlotte and one in Raleigh, both covering the topic of “Navigating Educational Scholarships and Financial Aid”. Adults and teenagers preparing for higher education learned about different scholarship opportunities available to them. We discussed scholarships specific to bleeding

disorders, but also information about what you need to be aware of when applying for financial aid that could help you to maximize your awards.

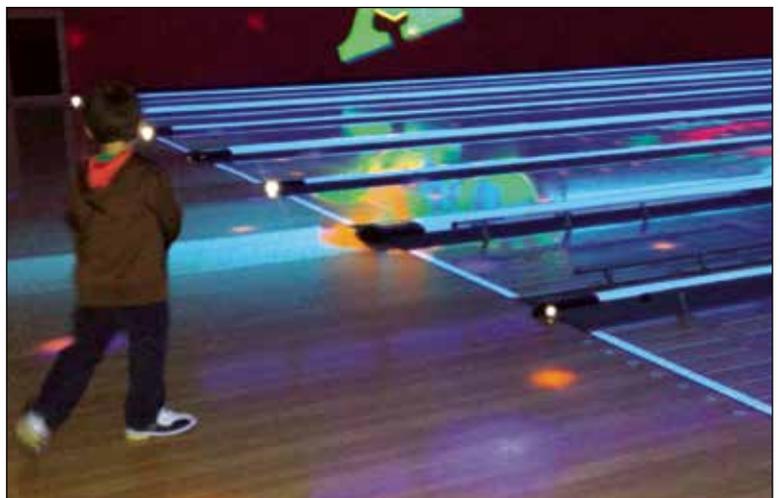
HNC is thankful to Baxalta and Biogen for their support and making these opportunities available.

## Charlotte Walk Kickoff at AMF

There was a lot of excitement in the room as people gathered and greeted each other at the Charlotte Walk Kickoff event on March 5th. Everyone was energized and ready to learn more about the 2nd Annual Charlotte Walk. Participants had time to mingle and get to know each other and talk about their Walk plans. Once the pizza lunch buffet was served and everyone had the opportunity to get some food, HNC staff took a few minutes to talk about the walk. Key items were discussed, including details about the Charlotte Walk and the importance of teamwork. The participants also had a chance to hear about where the money they’re raising will go. HNC is proud of the many programs and services offered to the community at no cost. From the retreats and one-day events to our financial assistance program, HNC has grown tremendously over the years to ensure the needs of the community are being met, thanks in large part to the support through our Walk efforts.

As the conversation wound down, it was time to BOWL! Even though nobody scored 300, everyone had a great time and left feeling like a winner.

For those who missed out on this fun kickoff event, there is always next year. But in the meantime, it’s time to get registered for the WALK: And kick start your fundraising to help meet this year’s goal of \$40,000 for the 2nd Annual Charlotte Walk! Don’t forget, for those who cannot make it to the Charlotte walk this year, mark your calendars for the Raleigh Walk on October 15th!



# HNC Casino Night: A Wager on Fun that Won!

January 30, 2016  
Charlotte, NC

Hemophilia of North Carolina (HNC) hosted our 9th annual “Hearts for Hemophilia” Casino Night event in Charlotte on Saturday, January 30th at the Big Chill. Charlotte was buzzing with excitement as they sent the Carolina Panthers off to the Super Bowl, so it was a perfect weekend for a fun-filled night of casino games, musical entertainment, superb food & drink and exciting auctions. Upon arrival, guests were greeted with a bright smile and \$20,000 worth of “fun money” to gamble the night away. The games this year included blackjack, craps, texas hold’em poker, and roulette. It was wonderful to see a mix of new and familiar faces as we gambled the night away, all for a good cause!

Some enjoyed the friendly competition at the gaming tables while others wagered to win at the silent auction, stopped by the open bar or joined in the fun of the photo booth. Wherever you chose to spend your time, folks really enjoyed the evening. The silent auction table was filled with a variety of gifts including: a luxurious hotel stay in Barbados, Vera Bradley bags, handcrafted artwork, several themed gift baskets, tickets to the NC Zoo, some spa & pampering certificates, and as always an opportunity to send a kid to camp. If you want to share in the fun, Casino Night pictures are now available on the HNC Facebook page.

The highlight of the evening was our live auction, which offered another chance to win even more unique items. The excitement jumped up a notch when the bidding began for the Carolina Panthers signed football, the Action Weekend in Charlotte, the Romantic Weekend in Asheville and the Weekend Getaway to the Jersey Shore. Most meaningful during the live auction was the opportunity to make a bid of financial contribution

to our emergency financial assistance program, a vital way of how HNC is able to assist the bleeding disorders community.

With plenty of opportunities to win great gifts, there weren’t many guests going home empty-handed. Even if you didn’t go home with your favorite auction



item or one of the plentiful raffle prizes, each attendee received a souvenir cup and some delicious chocolates as a thank you for their support and for being our guest for the evening. HNC raised over \$43,000 and all proceeds will help us to continue our goal of improving the quality of life for those affected by a bleeding disorder. It is our vision for everyone to achieve their full potential without barriers or limitations. Those that supported our event continue to make this vision a reality.

*Continued on page 7*



*Working to fulfill every need for every patient.*

For all of your hemophilia and inhibitor management needs call our specialist:

**Sam Byers** at (336) 327-4387  
**Tiffany Holland** at (980) 234-1260  
**Jecorei Lyons** at (615) 542-2571

We accept BCBSNC, Medicaid, Humana, Tricare, Anthem and many more.

*DrugCo Health is your local Southeast hemophilia specialty pharmacy.*



# HNC Casino Night *continued from page 6*

The HNC Board of Directors would like to acknowledge the hard work and tireless effort of many that helped make this event

possible. Thanks to our entire list of sponsors and individuals for continuing the casino night tradition!

**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for HNC's 2016 "Hearts for Hemophilia" Casino Night:**

**King of Hearts**

**Baxalta**

**Biogen**

**CSL Behring**  
Biotherapies for Life™

**Queen of Hearts**

**Bayer HealthCare**

**Drugco Health**

**Novo Nordisk**

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February 2016 USBS/MG155/15-0007b

**Baxalta**

## World Hemophilia Day Celebration: April 17, 2016

On April 17, we will be recognizing World Hemophilia Day. We will be raising awareness about bleeding disorders around the world. Did you know globally 1 in 1,000 people have a bleeding disorder? That is more than 7 million people worldwide. Most are not diagnosed and don't get treatment. Through World Hemophilia Day events, we can change that statistic, raise awareness, and increase the support for those living with a bleeding disorder around the world.

HNC will again be partnering with Biogen to light a building red in Charlotte, raise awareness for bleeding disorders, and honor the progress within our community. We'll be hosting family-friendly activities where you'll take part in the Factor Factory challenge, to build a working machine that brings to life the clotting cascade. Wear your red, bring your best funny face, and join us!



## WFH Congress and NHF Annual Meeting Announcements

It is a rare and special year for the bleeding disorders community of the U.S. to have the opportunity to attend both the World Federation of Hemophilia (WFH) Congress and National Hemophilia Federation (NHF) Annual Meeting in our own backyard. Details regarding dates, registration and travel grants can be found in the "On the National Front" section of this newsletter. While it is a considerable commitment of time and money, HNC would encourage all members to make the effort to be part of this exciting opportunity to witness the gathering of people affected by bleeding disorders, not only from around the nation, but also from throughout the world. You can find more about travel grants on page 26.

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**Tiffany Holland** at (980) 234-1260  
**Jecorei Lyons** at (615) 542-2571

We accept BCBSNC, Medicaid, Humana, Tricare, Anthem and many more.

*DrugCo Health is your local Southeast hemophilia specialty pharmacy.*



## Spreading Awareness One Nurse at a Time

HNC will once again be exhibiting at Nurses' Conferences in 2016 as a way to provide the nursing community with valuable information that will help them increase their knowledge of and ability to identify bleeding disorders and better serve those who are affected. HNC would like to thank the members who volunteer their time to get involved in this very important activity.

The first conference of the year, in April, is the North Carolina Nurse Practitioner Spring Symposium in Wilmington, NC. Between 300-350 nurse practitioners will be in attendance. HNC's presence at these events is an important opportunity to connect with some of

the most key people we may encounter regarding health and safety for those affected by a bleeding disorder.

While some nurses may be vaguely familiar with hemophilia, many are not as informed when it comes to von Willebrand Disease. The goal of this outreach program is to share information on all bleeding disorders by providing nurses with materials describing signs and symptoms of bleeding disorders, contact information for North Carolina's Hemophilia Treatment Centers and for Hemophilia of North Carolina, awareness flyers that may be hung in health rooms or bathrooms and other educational materials.



A well-educated nurse may be one of the first to notice the signs and symptoms of a person's bleeding disorder. It is our hope that by reaching out and sharing information at these conferences, we have better prepared them to do so.

Do you want to be a part of this important effort? Contact the HNC office to find out how you can help. Volunteers are needed to prepare materials and packets for handouts, be at the event to provide information and to make follow up calls after the event. In addition, HNC would like to thank CSL Behring for their continued efforts in making this important initiative possible.

## Calling all Adult Men: BBQ & Good Times!

HNC Men's Retreat  
Blowing Rock, NC  
June 10-12, 2016

### Who should attend?

- Fathers** whose child is affected by a bleeding disorder.
- Male caregivers** of a person with a bleeding disorder.
- Adult males** living with a bleeding disorder.

All of the above should join us for the weekend on June 10-12 in Blowing Rock, NC. This retreat will be designed to help our Blood Brothers, as well as fathers and caregivers of future Blood Brothers and Sisters, to connect with one another through roundtable discussions and with programming provided by Inalex Communications. It's a fun-filled weekend with great activities and, of course, great BBQ!

This retreat is designed to unite the men of the bleeding disorders community, who play a variety of roles and bring with them many unique viewpoints and experiences, so they can understand and support one another.

Registration and more details, including what fun activities we'll have (did we mention the BBQ?), will be available on the HNC website.



# HNC Legislative Day: One State, One Message in Need of Many Voices

*Alone we can do so little; together we can do so much. ~ Helen Keller*

Represent your State Legislative District at HNC Legislative Day on June 14th in Raleigh this year. On June 14th, members of Hemophilia of North Carolina will have an opportunity to attend this special day at the North Carolina State Capitol, so be on the lookout for announcements by email and on the HNC Website for updates and more information about how you can be part of this important event in our state. This year's session runs from April 25, 2016, through, June 30, 2016.

The focus of this year's HNC Legislative Day will be to build awareness and relationships among our North Carolina State Representatives and the bleeding disorders community throughout the state. The Advocacy Committee is continuing to meet monthly to prepare talking points for members to discuss with legislators at this year's Legislative Day. This is a wonderful opportunity to meet the people who represent us in our state government and discuss the issues that are important to you. Then, when new critical issues come up, you will already have a relationship with your legislator.

HNC is a statewide organization, so we need members from throughout the state to come to Raleigh and represent our community with their district representatives. What do you have to do? Share your story. A person of any age or legislative advocacy experience can succeed at telling his or her own story. Still not sure? Contact the HNC office to learn more. Need more inspiration? Read the article by Zack Hargett in this newsletter's "Young Voices" section, page 15.



Some HNC Advocates ran into Richard Petty at last year's Legislative Day.

## 2016 Friends of HNC

*We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2016.*

*We extend a sincere thank you to our supporters, some of who have contributed several times during this period.*

### General Donations

Charlene Cowell • Mr. & Mrs. Charles Cowell  
 Irene Cowell • Jen & Blair Fisher  
 Mr. & Mrs. W. Allen Heafner • Matthew Manlove  
 Alisha Moore • Carrie Regler • Gillian Schultz

### In Memory of David Paul Vess

Mr. & Mrs. Bobby Bingham

### In Memory of James Timothy "Timmy" Neal

Mr. & Mrs. Harold Clements



*Thank You*



### MEDICAL ALERT StrapWrap®

Designed especially for people with bleeding disorders, StrapWrap® attracts the attention of emergency personnel while it protects confidential medical information inside. StrapWrap® fastens with Velcro® so you can use it on a seatbelt, backpack or baby carrier.

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[BioRxHemophilia.com](http://BioRxHemophilia.com)

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# Teen Retreat: Carolina Crew is at it again!

Camp Canaan – Rock Hill, SC  
July 7-10, 2016

Calling all teens (ages 13-18)! Save the date for July 7-10 for the next joint Teen Retreat with HNC and HSC, also known as the Carolina Crew (coined by teens back in 2013). Not only did we listen to the attendee feedback about staying at the same location but we also extended the retreat another full day! Do you remember Pat Torrey aka “Big Dog”? You’ll get to meet his

brother, Joe, who will be leading this year’s retreat – and we’ll get to find out his nickname!

As always, this is a fun, educational weekend designed especially for teens in the community. If you’ve never been to one of our Teen Retreats, please check out the HNC Facebook page for photos. The Retreat is a great opportunity to make new friends, share laughs, challenge yourself and prepare for your future.



We will provide busing from certain parts of the state, locations TBD based on registrations. Teens can bring one friend or family member with them (she/he must also be a teen). All of the details will be available on the HNC website as soon as possible, but please contact the HNC office if you’re interested in hearing more about the weekend. This will help us to ensure we select the most popular pick-up locations for busing.

## Want to Know More

about your factor options?



When it comes to your factor therapy, you have choices. And at Biogen, 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:

**Nikita Lyons Murry** | Phone: 615.525.1003 | E-mail: [Nikita.Lyonsmurry@biogen.com](mailto:Nikita.Lyonsmurry@biogen.com)

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# Charlotte & Raleigh Walks in 2016



You may have heard it before, but it's worth saying again. We're only as strong as our community, and both the Charlotte and Raleigh 5K Walk fundraisers continue to show just how united we are! Since 2008, when the National Hemophilia Foundation (NHF) asked HNC to be one of the first five walk sites in the country, it would have been impossible to guess that just

nine years later, North Carolina would grow to have two annual Walks and become one of the top fundraisers across the country! HNC's members, supporters and sponsors should be extremely proud of the role they play in this achievement. From the bottom of our hearts we thank you all for your efforts to help HNC and the bleeding disorders community of North Carolina.

The 2nd Annual Charlotte Walk is just around the corner! It's not too late to join us as a walker or volunteer on April 16th in Uptown Charlotte, starting at the corner of 3rd Street & MLK Blvd. The Charlotte Knight's Mascot, Homer the Dragon, will be there to send the walkers off on their 5K route through the streets of Charlotte and around Bank of America Stadium. It will be the largest gathering of HNC members and supporters in the Charlotte area in 2016, so bring your family, friends and 4-legged companions out to support the community and build awareness.



If you can't make it to Charlotte in April, or if you'd like to participate in TWO Walks this year, registration is now open for the 9th Annual Raleigh Walk to be held on October 15th at Lake Crabtree County Park in Morrisville, NC. This 5K walk in the park will be just as much fun as it's always been, so please plan to be there and see for yourself how great it is to be part of this supportive community!

Whether you choose to walk in Charlotte, Raleigh or both, we can't wait to walk with you again this year!

Info is available at [www.hemophilia-nc.org](http://www.hemophilia-nc.org) for both Walks. The site features information for walkers, sponsors, teams and volunteers. Printed Sponsorship and Team Captain Packets are also available in English and Spanish through HNC by calling 800-990-5557 or by email at [walk@hemophilia-nc.org](mailto:walk@hemophilia-nc.org).



## Other dates to Save!

**Blood Brotherhood  
Retreat**  
Beach Location  
September 23-25, 2016

**HNC Family Retreat**  
Lake Junaluska, NC  
September 30-October 2,  
2016

**Inhibitor Family Camp**  
Victory Junction Camp  
Randleman, NC  
October 7-9, 2016

**Raleigh Walk**  
Morrisville, NC  
October 15, 2016

**HNC Yard Sale**  
Morrisville, NC  
October 22, 2016

**HNC Holiday  
Celebration**  
Jamestown, NC  
December 3, 2016

*\*Check HNC website  
for all dates*

## Próximos eventos – Unión Latina

Seguimos preparando algunos eventos y programas para ti.

El 9 de abril en el Zoológico de NC, en Asheboro, NC, Patricia Espinosa-Thomson presentará el programa titulado “No Sweat-Staying Active and Healthy (Activo y sano sin sudor)”. Además de esta interesante presentación, tendremos tiempo para recorrer el zoológico y pasar un día increíble todos juntos.

El 14 de mayo en el Sheraton Greensboro, NC, se llevará a cabo La Reunión Anual de HNC. Este es el evento más importante de Hemofilia que reúne a los miembros en todo el estado. Para este año tendremos sesiones para adultos, niños y además sesiones en español!

Prepárate para el próximo evento de Unión Latina el próximo 18 de Junio en Charlotte, NC. A partir de las 4:00pm hablaremos sobre “Hemofilia y un sano envejecimiento” y podrás acompañarlo con una rica cena adelantada. Para finalizar el evento, iremos al BB&T Ballpark a un juego de beisbol de los Charlotte Knights.

El 24 de septiembre será un día muy especial ya que celebraremos el Día de Muertos por adelantado. Habrá lunch, convivencia, juegos y tendremos la presentación “Comparte tu historia”. Sera un evento en el que conmemoraremos una fecha importante que es parte de nuestra tradición. Este evento se llevará a cabo en las oficinas de HNC en Morrisville, NC.

El 3 de diciembre será nuestra Fiesta de Navidad en Castle McCulloch en Jamestown (cerca de Greensboro). Tendremos



comida, bebidas, regalos para los niños y mucha diversión. Después de la fiesta habrá otro evento. Durante la media noche presentaremos el programa “Food for thought (alimento para el pensamiento)” y lo acompañaremos con una rica cena. Será una gran noche!

Te esperamos pronto!

### La Caminata de Hemofilia Ahora en Español!

Gracias a nuestro amigo Daniel León, todos los documentos de La Caminata ahora están disponibles en tu idioma. Con un solo clic puedes acceder a la versión en español y conocer más detalles sobre este gran evento.

## 68ª Reunión Anual de NHF y Congreso Mundial de WFH

Aun puedes registrarte para la 68ª Reunión Anual de NHF “A Brighter Future Together” del 21 al 23 de Julio, 2016, y para el Congreso Mundial 2016 de WFH del 24 al 28 de Julio, 2016 en Orlando, Florida. La Reunión Anual de NHF se llevará a cabo en Gaylord Palms Resort & Convention Center, mientras que el Congreso Mundial de WFH en Orange County Convention Center.

Se espera que sea un evento grandioso ya que por primera vez en más de 20 años, desde que revocaron prohibir la entrada a EUA a personas con VIH SIDA, la comunidad de personas con trastornos hemorrágicos de todo el mundo se reúnen en los Estados Unidos. Hemofilia de Carolina del Norte sabe que asistir a un evento de esta magnitud implica tiempo y dinero, pero te invitamos a que consideres la posibilidad. Este evento será único por lo que vale la hacer un esfuerzo extra para asistir al Congreso Mundial de WFH y la Reunión Anual de NHF.

Si estas interesado en asistir al evento, llámanos pronto ya que apoyaremos económicamente a algunos miembros. Las

aplicaciones para el apoyo económico están disponibles en nuestro sitio web en la sección Programas y Servicios.

Visita los sitios web y regístrate.

- Congreso Mundial de WFH: [www.wfh.org/congress](http://www.wfh.org/congress)
- 68ª Reunión Anual de NHF: visita [www.hemophilia.org](http://www.hemophilia.org), elige “Events & Educational Programs” y da clic en “NHF’s 68th Annual Meeting”



# SOARting Out Our Next Steps

As the title hints, we are in planning stages for the SOAR Program in 2016 and beyond. Although there have been some gatherings over the past year at the Annual Meeting, dinners and nurses conferences, HNC recognizes that we can do more in 2016 with regard to female-specific programming, and we plan to do just that!



Currently, we are planning several focus groups and brainstorming sessions across the state so that we can revitalize the SOAR Program and make it the best that it can be. We want to hear from you. Through these, we will determine the future of SOAR so that it can meet your needs. We expect to hit five geographical areas across the state to be sure that no one's left out! Stay tuned to the HNC website and Facebook page over the next couple of months for more information. We will also be sending out a needs assessment in the next couple of months. Please be sure to complete it and return it to the HNC office.

Although we are enjoying all that Spring has to offer North Carolina and are just about to wrap up the 2nd Annual Charlotte Walk, we are already planning for the 9th Annual Raleigh Walk in October. As in previous years, we will be selling tutus to benefit the SOAR Program, and we need your support helping

us to make the tutus. These tutus are now known symbolic representations of affected women and girls at the Walk. Just let us know if you are willing to help, and we will be happy to get you started! Another way to support this program is to join the SOAR team for the walk if you don't already have one!

To further our efforts in enhancing SOAR in 2016, HNC completed a Victory for Women series through the National Hemophilia Foundation (NHF). This program helped to focus ideas on future programming, hear from other organizations across the country, and even gave us a chance to "toot our own horn!" as we shared the wonderful things that the SOAR Program has done over the years as a truly grassroots group to support and raise awareness about women with bleeding disorders.

SOAR is an HNC Program for women and girls who are personally affected by a bleeding disorder. 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. For more information, contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@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](mailto: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*



*Our Young Voices* is the latest supplement added to *The Concentrate*. It is designed to be a platform for the voice of youth that are a part of the Hemophilia of North Carolina (HNC) community. This supplement will feature creative writing, drawings and news *for* our youth, *from* our youth. If you are a young voice of HNC and would like to submit a written piece or visual art for upcoming issues, please contact HNC Staff at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).



## Welcome to Washington

*By: Zack Hargett, age 5*

I was diagnosed with hemophilia A at 5½ months old. I attended my first Washington Days 4 years ago in 2012. This year at Washington Days we met with Matthew Flynn, with Thom Tillis staff. We shared our stories about hemophilia and talked about HR3742 bill, which has to do with third party payments. Then we met with Mark Walker. We found out that North Carolina produces a lot of peanuts. He was very Kind. I got to see his Duke basketball with a lot of signatures on it. We also talked to Mark about the same thing as Matthew Flynn. Mark gave me a coin with a picture of the capitol dome. We got to ride a train under all the buildings. It was very fast and fun. We had to get a special badges to ride the train. Look at all the fun you can have Kids while doing something good for the community.





**Space may still be available at these Summer Camps!**  
**Please follow instructions listed for each camp to access applications.**

## Victory Junction Camp in Randleman, NC

**June 12-16:** *Sickle Cell Anemia and Bleeding Disorders*

**July 3-6:** *Neurological and Genetic Disorders*

For information additional information about how to register go to [www.victoryjunction.org](http://www.victoryjunction.org) or call 336-498-9055.

## Camp Carefree in Stokesdale, NC

For information about Camp Carefree, the services they provide year-round or to find out if space is still available at the Camp Weeks listed below, go to [www.campcarefree.org](http://www.campcarefree.org), email [carefreedirectors@gmail.com](mailto:carefreedirectors@gmail.com) or call 336-427-0966.

**June 19 – June 25, 2016:** *Siblings Camp*

**July 17 – July 23, 2016:** *Kids Camp*

**July 24 – July 30, 2016:** *Hemophilia, blood disorders, vWD & Turner's Camp*

## Camp Rainbow at Camp Don-Lee in Arapahoe, NC

Camp Rainbow is available to patients of the East Carolina University Hemophilia Treatment Center (ECU HTC) in Greenville, NC. For information about Camp Rainbow or to find out if space is still available in the Summer Session this year, please call the ECU Hemophilia Treatment Center at (252)744-4676 or visit their website at [www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm](http://www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm)

**June 12-June 18, 2016**



## Looking Ahead *continued from page 1*

As Spring unfolds into Summer, then Fall and straight through to the end of the year, HNC continues to plan programs and activities for the community. Please review the HNC News section of this issue of The Concentrate, so you and your family can plan to join us! You can always find up-to-date information on our website calendar or by calling the HNC office. Please also call us with your ideas for programs and/or events!

Here is an overview of what you can expect in the upcoming months: The Charlotte Walk and World Hemophilia Day Celebration will be in Charlotte this April, with the HNC Annual Meeting in Greensboro in May. Moving on to summer, the Legislative Day in



June, Teen Retreat & Men's Retreat will be held at various locations throughout the state in July. After that, HNC will be offering the Blood Brotherhood Retreat and the Family Retreat, both scheduled for September. The Raleigh Walk and HNC Yard Sale follow in October, and the year winds down with the HNC Holiday Celebration once again at Castle McCulloch this December.

These are just a few of the many programs and events HNC is working on for members to look forward to throughout the rest of 2016. Please feel free to contact the HNC office for more information about any events taking place in your backyard. Whether it's your 20th year or your first, there is always a place for you!

# HNC 43rd Annual Meeting

*continued from page 1*

to say the least. We need to continue honoring the older generations who are responsible for many liberties we have today, including the safe products that we use. Hemophilia Federation of America (HFA) will tell us more during their presentation at our Annual Meeting. It is sure to make an impact.

It is also important that we look toward the future to see what's already in the pipeline and, most importantly, what we want for our community moving forward. Every organization and business working within the bleeding disorders community, including HNC, is driven by consumer input; so we need you to join the effort to determine what our future will look like! At the Annual Meeting, you'll have a chance to learn more and also to provide your insights. When it comes to this, you are the experts!



What else can you look forward to at the HNC 43rd Annual Meeting?

- ~ Childcare for ALL ages
- ~ Teen Track
  - HFA programming
  - Junior Scientist program, sponsored by Accredo, will discuss the molecular structure of cells and the mysteries of DNA. The role that genetics plays in determining inheritance of a bleeding disorder will be explored. A scientific experiment will be done to show actual DNA.
- ~ First-time attendee session (includes hotel stay on Friday and gas card to be distributed at the end of the session on Saturday)
  - There will be a special session in the morning for anyone who has never been to one of HNC's Annual Meetings. Whether you are new to the community or have just never experienced our Annual Meeting, we encourage you to join us for the morning "First-time Attendee" session.

- If you are a first-time attendee, please indicate this on your registration application form. HNC will contact you about a hotel room for Friday night and about BP gas cards to help with your travel costs. Hotel room payment vouchers and gas cards will be distributed at the First-Time Attendee Session, so you must be present to receive these added benefits.

- ~ Traductores estaran disponible en la reunion para asistirle en Español
- ~ Breakout sessions include:
  - SOAR (women) – *for women and girls with bleeding disorders*
  - Blood Brotherhood – *for adult men with bleeding disorders*
  - HOPE (families) – *for parents of children with bleeding disorders*
  - Spouses/Caregivers/Loved Ones
  - Latin Union – *focused on providing resources to Latino/a individuals and who are affected by a bleeding disorder*
  - Social Media
  - Inhibitors
- ~ Raffles and Door Prizes – and lots of them!

Do not miss this important event; it only comes once a year! Registration is open on the website! Call the HNC office if you have any questions about this important meeting.



# HNC Member in the News - George McCoy

By: Caitlin Knute, ABC11

## Local Man at the Forefront of Hemophilia Research

At the age of 68, George McCoy has been through more physical hardships than most. But, over the years he's refused to give up, fighting to overcome the obstacles life has thrown at him, going on to be a sort of medical pioneer in the field of treating hemophilia.

"I was born in 1947 and at that time there was no real understanding of hemophilia, there was no treatment. So, my childhood was full of ice bags and sitting with an ice bucket in front of me, putting my ankle in it, long nights of no sleep, and a lot of missed school, a lot of restricted activity," he recalled.

Hemophilia is a rare disorder where blood doesn't clot properly because it lacks sufficient blood-clotting proteins (otherwise known as clotting factors.) There are two types, Hemophilia A (accounting for roughly 80% of patients) and Hemophilia B (which represents approximately 20% of cases.) This genetic disease, which predominantly affects men, causes patients to bleed for much longer than a typical person following an injury. Smaller, superficial cuts aren't the primary concern.



Instead, the greater concern is internal bleeding, which can damage organs, tissues, and joints. For McCoy, the lack of treatment available during his youth made him dependent on full leg braces, crutches, and even a wheelchair to get around.

"Once the blood would get into the joints in an untreated person with hemophilia, which is what I was, there was a huge swelling of the joint. The skin would become very tight, very hot, it was very painful, and the joint lost all movement. So, by the time the body recovered and

cleaned all of that up, and reduced the swelling, you were left with joint damage," he described.

But, upon searching for answers to his ailments while in college, McCoy realized there might be doctors who could help him.

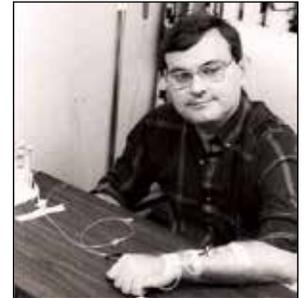
"In researching hemophilia, I saw footnote after footnote of 'UNC Chapel Hill, UNC Chapel Hill.' So, as soon as I was able after college I relocated here, deliberately to participate in research," he said.

Because this was in an age long before the internet and Google searches, McCoy had to find doctors the old-fashioned way, using a phone book. His persistence paid off, and he connected with staff at UNC, immediately volunteering to enroll in research efforts. The first benefit of this was that doctors addressed the orthopedic side

effects of his hemophilia and got him walking again. And, for a time his hemophilia was successfully managed through infusions of clotting factors derived from plasma donations. Then, catastrophe struck the hemophilia community.

"It was realized in the early 80s that a clotting factor could transmit the HIV virus because clotting factors were made from pooled human plasma. It was a disaster, and 10,000 hemophilia patients in this country out of 25,000 got infected with HIV," explained Nigel Key, MD, PhD, the Director of UNC's Hemophilia and Thrombosis Center.

McCoy, unfortunately, was one of those who became infected with not only HIV but also Hepatitis-C. He says many of his friends from those days didn't make it. But he did, and despite the health scare,



Picture of George receiving the first synthetic clotting factors in the world

Member in the News Continued on page 19

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## HNC Member in the News

*continued from page 18*

he didn't hesitate when UNC contacted him to see if he'd once again participate in their research.

"UNC called me and said, 'we have this new form of clotting factors, recombinant, that's genetically engineered, made in a laboratory with no human involvement. You'd be the first person to try this.' And I said yes. By that time, I was already HIV and hepatitis C infected. So, I felt it was good for me to take the gamble, what did I have to lose? And I had a great deal to gain, as did our whole hemophilia community," George shared.

And that gamble paid off. As the first person in the world to receive the man-made clotting factors back in 1987, he helped pave the way for what is now the current standard treatment. And now, he's once again on the frontlines of the latest advancement in treatment, currently taking the next generation of man-made clotting factors which allow patients to go longer between infusions.

"I have gone from three treatments a week to two treatments a week. I realize to the casual observer that's nothing, but to me it's 52 fewer vein punctures a year. Actually more, because as many years as I've been doing this I still miss the vein from time to time," he admitted.

Dr. Key calls these latest products a major breakthrough, especially for patients with Hemophilia B, who are able to now go from two injections a week to twice a month.

"There's never been a pipeline like there is now, and I think the ability of science and biotechnology to translate into meaningful protein therapies and gene therapies is really amazing these days," said Dr. Key. "We've had the promise of gene therapy for 15 years but it's becoming more of a reality, and UNC has been a leader in that."

In fact, there's a gene therapy building near Key's office where they actually make the vector for ongoing trials. Key explained this is exciting because it could be the key to finally finding a cure.

"Potentially it could be a one-time treatment for life, and I really think that's coming in the next, not two years, but the next decade," he said with confident optimism.

For McCoy, it's a possibility he's been waiting for his entire life.

"My personal goal is that, indeed, I will be able to live from the age of 1947, the dark ages, to the day when, in fact, we do have genetic control. And if I don't make it, I'm sure that someone is already alive today who will be able to expect that breakthrough, and I will be proud of the role that UNC and I have played in getting to that day," he said.

*NHF Issue Brief Source: ABC 11 (NC)  
February 16, 2016  
<http://abc11.com/1202659/>*

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# HOPE Program Update for Families

- *Help*
- *Opportunity*
- *Partnership*
- *Empowerment*

HNC's HOPE Program is raring to go with two major events coming up in the next 6 months! We are happy to announce HNC's first-ever Family Fun Day. This is

going to be a fun day out for the family where you will have the opportunity to meet and mingle with others who also have a child with a bleeding disorder. Expect a fun, social outing. Stay tuned to the HNC website and Facebook page for more information about Family Fun Day.



The other HOPE event for which planning has already begun is the 2016 Family Retreat. This year's retreat will be September 30-October 2. We'll be returning to Lake Junaluska in the mountains west of Asheville for another great event so save the date! The Family Retreat is a weekend of education and networking for families with a child up to the age of 12 with a bleeding disorder. We

will have programs for adults and children including childcare for our youngest members. Thanks to the support of sponsors, there is no fee to attend the Family Retreat. We hope to see you and your family there!

In the next couple of months, you will be receiving a needs assessment about what you need and would like to see from the HNC HOPE Program. When you get the assessment, please take a couple of minutes to complete the form. It will help us to plan programs and services for you as we move forward.

HOPE stands for *Help, Opportunity, Partnership, Empowerment*. The mission of HOPE is to improve the quality of life for families of the newly diagnosed through the age of twelve with bleeding disorders, so that they may HOPE to lead a fulfilling life. Together, with a community of other parents/caregivers we can support each other so that both parent and child can feel empowered, and not limited by a bleeding disorder. Open to any member of HNC, HOPE programs are geared specifically towards parents with children in this age range. For more information about the HOPE Program, or if you have ideas for programs and events, please contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or contact the HNC office at (800) 990-5557. You may also check the HNC webpage, Facebook and/or Twitter page for updates on upcoming programs and events.

## Latin Union Program Update

We are again planning for some great programs across the state.

On April 9, the Latin Union will be at the N.C. Zoo. Patricia Espinosa-Thomson will be presenting a program entitled "No Sweat-Staying Active and Healthy". After lunch and the presentation guests will get to catch up with one another and enjoy the zoo.

The HNC Annual Meeting will be held May 14 at the Sheraton Greensboro. This is our largest educational event that brings people together from across the state. There will be programming for adults and children, including some sessions in Spanish.

On June 18, join us in Charlotte for the next Latin Union Program event. We will have an early dinner at 4:00pm and hear about Healthy Aging and Hemophilia. Following dinner, you can enjoy a Charlotte Knights baseball game.

After a long summer, everyone will be excited to get together again on September 24 at the HNC office in Morrisville for an early Day of the Dead celebration. We'll have lunch, games, and a presentation

"Sharing your Story" so that we can continue to advocate for our family and ourselves.

Spend December 3 at Castle McCulloch in Jamestown (near Greensboro) for the Annual Holiday Celebration, featuring food and presents for all the kids. Following the Holiday Celebration, join us for dinner that night, an overnight stay and a "Food for Thought" program on Sunday, December 4. We'll see you soon!





# Blood Brotherhood Update

We are pleased to announce our first Blood Brotherhood meeting of 2016! Come join the guys for Movie Night on April 16th in Charlotte, NC, after the Walk concludes! Dinner and a movie together at the wonderful Studio Movie Grill offers dining right in the theatre so you don't miss any of the action. This event is designed to create a social atmosphere for adult men living with bleeding disorders to share experiences, develop a support system and become friends.

As always, thanks to Hemophilia Federation of America (HFA) for presenting this program and opportunity here in NC and many other states. Can't make the event in April? No worries, HFA offers an online forum and chat session just for Blood Brothers.

For more information on Blood Brotherhood nationally, including information on the private online forum for adult men with bleeding disorders, and the online Blood Brotherhood Chats, visit: [www.hemophiliafed.org/programs/blood-brotherhood](http://www.hemophiliafed.org/programs/blood-brotherhood)

For more information on Blood Brotherhood locally, visit the HNC website [www.hemophilia-nc.org](http://www.hemophilia-nc.org), and save the date for our 2016 Blood Brotherhood events here in NC:

- May 14 - Greensboro, NC (HNC Annual Meeting)
- June 10-12 - Blowing Rock, NC (HNC Men's Retreat)
- September 23-25 - Beach Location (HNC Blood Brotherhood Retreat)
- November 19 - Chapel Hill, NC
- And more...



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Date of preparation: 1/2016. NUW-017-CAD-b



# richard's review

By: Richard J. Atwood, HNC Volunteer

## Disclosing Hemophilia: Mario Giannini

Privacy concerning your personal health information is paramount in the world of healthcare, insurance, and employment. For example, what would you disclose to your employer about your bleeding disorder? In some cases, you might need to disclose. What if you were a prominent public figure, like Bill Gates or Brad Pitt? How might your disclosure affect your business? Consider Lawrence Mario Giannini, who had hemophilia and was president of the world's largest private bank.

Mario was born in San Francisco in 1894. His father, Amadeo Peter Giannini, known as A.P., founded the Bank of Italy in 1904. A.P. began by serving the Italian immigrants in San Francisco and then expanded banking services across California by acquiring other banks. In 1930, his bank's name changed to Bank of America.

The Giannini family moved to San Mateo, California, in 1910. Of the eight children born to A.P. and his wife, Clorinda, only three lived to adulthood. Both surviving sons, Mario and his younger brother Virgil, had hemophilia. At that time, there was no known family history of hemophilia for these second-generation immigrants from Genoa, Italy.

A.P. worried about his two sons with hemophilia, who were not robust like their father. No records are known to exist describing how the young boys coped with their bleeding condition. By age 32, Mario had suffered frequent hemorrhages. In a nonmedical summary, he is described as having bent, stiff hips along with twisted and crippled legs. He walked with a cane. Without access to any medical records, we have to surmise that Mario might have suffered from several conditions, such as limited range of motion in his knee joints, loss of muscle mass, a shortened leg, or shortened Achilles tendons.

But nothing seemed to stop Mario from his profession. He always wanted to be a banker, and he succeeded based on his skills, not because of his father's influence. After graduating summa cum laude from the University of California—Berkeley and then from Hastings School of Law in 1920, Mario worked at the Bank of Italy as his father's personal assistant. Advancing over the next 10 years, Mario was elected president of Transamerica

Corporation, the holding company for the banking empire. In 1932 Mario was appointed senior vice president, and two years later was elected president of Bank of America, then the nation's largest bank. He remained its president until he died in 1952. Ever expanding, Bank of America became the largest private bank in the world by 1945, and remained so for the next twenty years.

Mario devoted himself to a brutal work schedule. He could work from his apartment on California Street on Nob Hill, and later from his apartment on Green Street on Russian Hill, when he could not make it to the bank's downtown office. This may not have been bank policy then, but it resembles today's effective practice of working remotely from home.

In 1928 Mario hemorrhaged badly in the thigh muscles of both legs. He received repeated transfusions of whole blood, which stabilized the bleeding but left the joints in both legs swollen and painful. A month later, Mario was admitted to St. Francis Hospital to undergo orthopedic treatment. His specific treatment is not recorded, but he probably underwent corrections for fixed flexion contracture of the knees (inability to straighten), and possibly tendon and ligament lengthening using casts, splints, and slings.

Though immobilized in bed for several months, Mario continued to conduct bank business from his hospital room. During his recovery, as he started to walk again with a cane, Mario fell in love with a nurse named Mercedes Anne Collins. Mario married Mercedes in 1929, and they had two daughters and lived in Atherton, California.

Mario received recognition for his accomplishments. He earned Italy's highest civilian medal. President Harry Truman offered Mario an appointment as secretary of defense, which he refused, and an appointment to the Foreign Trade Financing Commission, which he accepted. Mario took his father's position as a University of California regent, though he later resigned during a controversy over academic freedom.

Mario's health challenges continued, especially affected by legal battles as he fought accusations by the Federal Reserve

*richard's review Continued on page 23*

*richard's review* continued from page 22

Board that Transamerica was a banking monopoly. This stressful legal dispute included frequent cross-country trips to testify in Washington, DC. The bank, however, did not publicize Mario's medical condition. Mario anticipated retiring at age 60 in 1954.

While in Palm Springs in 1952 with a family friend, Mario had another medical crisis. On March 10 he flew back to San Francisco to be admitted at Franklin Hospital. His physician reported that the hospital admission was for treatment of arthritis. (Another report listed the reason for admission as an operation for hemorrhoids, which may have been confused with hemorrhage or hemophilic arthropathy.) For this admission, the press reported Mario's medical condition, but the information wasn't always accurate. Mario never left the hospital. He contracted influenza that developed into viral pneumonia. While in critical care, Mario died of a heart attack on August 19, 1952, at age 57.

Not everyone grows up to head the world's largest bank. Mario Giannini lived in an era with less scrutiny of personal health issues than is possible today, with our 24/7 invasive news cycle. Mario's hemophilia was known, yet it was not publicized by him, by his family, or by the bank, so details about his medical condition are sparse. For a current comparison, recall how the eagerly awaited press release reports of Steve Jobs's cancer condition affected speculation about buying and selling Apple stock. If you're a public figure today, the fact that everyone knows your health status can affect your personal life, your privacy, and your career. For most of us, what personal health information we reveal is our decision. Prepare ahead of time what you might disclose about your bleeding disorder, depending on your type of employment and where you work.

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# Researchers Make Gene Therapy Breakthrough in Dogs with Factor VII Deficiency

In a recently published paper in the journal *Blood*, a team of researchers from the University of North Carolina (UNC) and The Children's Hospital of Philadelphia (CHOP) reported the successful application of gene therapy in dogs with factor VII (FVII) deficiency. This represents a significant advance, demonstrating the safety and efficacy of a novel therapy in large animal studies is a standard precursor to eventual clinical trials in humans.

FVII deficiency is a rare bleeding disorder with an incidence of 1 in 300,000 to 500,000, as both parents need to carry the gene in order to pass it on to their children. The condition, which affects men and women equally, is characterized by inadequate production of the FVII clotting protein. Babies are often diagnosed within the first six months of life after sustaining an intracranial hemorrhage or bleeding in the gastrointestinal tract. People with the more severe form of FVII deficiency often experience joint and muscle bleeds, easy bruising and bleeds after surgery. Bleeding can also occur in the skin, mouth, nose and genitourinary tract, while women often experience severe menorrhagia (prolonged, heavy periods). The primary treatment for FVII deficiency is recombinant factor VIIa.

The study, "Sustained Correction of FVII Deficiency in Dogs Using AAV-Mediated Expression of Zymogen FVII," was published in the February 4, 2016 issue of *Blood*. The senior investigator was Paris Margaritis, D.Phil., head researcher at CHOP and Penn's Perelman School of Medicine. Leading the UNC team was Tim Nichols, MD, professor of medicine and pathology at the UNC School of Medicine.

For the study, Margaritis cloned the canine factor VII gene and enclosed that genetic material inside adeno-associated viruses (AAVs). These viruses act as delivery vehicles, or vectors, to carry the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses. In this case, the AAVs are designed to elicit the production of the FVII. Nichols and his colleagues then treated four FVII deficient dogs with a single injection of the therapy, administering different amounts of AAVs in each of the animals.

They found that the amount of factor VII generated was directly proportional to the amount of AAVs given to the individual dogs. Nichols's team also monitored the dogs' progress over a period of three years and found that they all produced FVII levels that were sufficiently therapeutic – this is particularly encouraging for investigators as the amount of FVII necessary to achieve a sustained therapeutic effect in dogs correlates closely to that for humans.

"This work is very exciting and promising," said Nichols. "The FVII-deficient dogs tolerated the initial gene therapy infusions very well and have had no adverse side effects over several years of follow up. In other related studies in dogs with hemophilia B (FIX), similar positive findings have translated to people with hemophilia B."

In addition, blood, kidney and liver function tests all showed that therapy was safe and did not trigger an unwanted immune response. The next step will be to conduct clinical trials in humans. "The table is now set to propose clinical trials that would treat people who suffer from FVII deficiency," concluded Nichols.

Source: UNC Health Care news release dated January 20, 2016

Reprinted from: <https://www.hemophilia.org/Newsroom/Medical-News/Researchers-Make-Gen-Therapy-Breakthrough-in-Dogs-with-Factor-VII-Deficiency> on February 12, 2016



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# The Importance of NHF's Washington Days

Advocating is one of the most important civic responsibilities we have, especially within the bleeding disorders community. We are only as strong as the people who join together to advocate for themselves and their loved ones. The community was united on February 24-26th at the National Hemophilia Foundation (NHF) Washington Days event, where over 350 advocates met with their representatives and congresspersons to talk about issues impacting the bleeding disorder community. It is a unique opportunity to get involved with advocacy at the national level along with fellow members from all over the country.



*Twelve people in one elevator, and there's still room for you!*



Twelve people from around the state, with varying legislative advocacy experience, represented North Carolina. We had eight meetings throughout the day, including a meeting with the staffers of both of our NC Senators. The Hargett family had an opportunity to talk with Representative Walker and one of the Hargett's sons, Zack, proudly showed his port to those who were interested. You can read Zack's recap on page 15. Our major talking points for 2016 were:

1. Participate in the Red Tie Challenge by doing a one-minute floor speech in honor of Bleeding Disorders Awareness Month or posting a photo wearing the red tie on their social media channels;
2. Support funding for the hemophilia programs at CDC and HRSA in their appropriations requests;
3. Co-sponsor the Access to Marketplace Insurance Act (HR 3742 in the House) or introduce companion legislation (Senate) to ensure that people enrolled in the qualified health plans (QHPs) offered on the ACA marketplace plans can continue to work with non-profit third-party patient assistance organizations.

We want to thank all of those involved at Washington Days and those advocates at the state level back home for continuing to ensure the bleeding disorders community is well-represented. Hemophilia

of NC (HNC) is fortunate to have an established and knowledgeable Advocacy Committee that meets (via conference call) monthly to talk about issues but we need YOU! As our group gets larger, we have more constituents to meet with their legislators and share their stories. A person of any age or legislative advocacy experience can succeed. We will be there to educate and support you. Look at Zack Hargett; he is already a professional advocate at 5 years old!

## Bleeding Disorders Awareness Month



HNC is pleased to announce that the National Hemophilia Foundation (NHF) has made a huge step as an advocate for all people affected by bleeding disorders in their successful petition to have Bleeding Disorders Awareness Month placed on the National Health Observances list for March.

While efforts have routinely been made to increase awareness for all bleeding disorders during what has been known every March since 1986 as Hemophilia Awareness Month, this change is a milestone for the community as a whole. Members who are affected by hemophilia, von Willebrand disease or another factor deficiency, can now feel they too are represented by the name of this month-long period of building awareness!

## 2016 WFH Congress and NHF Annual Meeting Announcements

Registration is still open for the National Hemophilia Foundation's (NHF) 68th Annual Meeting, *A Brighter Future Together*, from July 21–23 and the World Federation of Hemophilia (WFH) World Congress taking place directly following from July 24–28, both in Orlando, FL. The NHF Annual Meeting will be held at the beautiful Gaylord Palms Resort & Convention Center and the WFH World Congress will take place at the Orange County Convention Center.

It promises to be an exciting event as the bleeding disorders community from around the nation and throughout the world gather together in the United States. This is the first time in more than 20 years a gathering like this has taken place in the U.S. since the ban on individuals with HIV visiting the United States was lifted a few years ago. Members are strongly encouraged to explore the possibility of attending. HNC and all members of the bleeding disorders community should be looking forward to this rare opportunity to attend both the WFH Congress and NHF Annual Meeting in this country!

HNC realizes that attending this conference is a substantial commitment of time and money. **HNC has grants available for members to attend these events, so give us a call if you're interested in attending! Grant applications are available on the Programs & Services page of the HNC Website.**

To register for either the WFH World Congress or the NHF Annual Meeting, please visit these websites.

- WFH Congress: register through [www.wfh.org/congress](http://www.wfh.org/congress)
- NHF Annual Meeting: from the [www.hemophilia.org](http://www.hemophilia.org) website, use the "Events & Educational Programs" tab and click "NHF's 68th Annual Meeting"

Don't forget your medicine . . . and your sunscreen!



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**Donate to the Walk**

You can make an online donation to HNC's 2016 Hemophilia Walk through the National Hemophilia Foundation web site. Just follow these easy steps:

- Go to [www.hemophilia.org/walk](http://www.hemophilia.org/walk)
- Click **NC Charlotte** (or **NC Raleigh**) near the lower right-hand corner.
- Click on the blue **DONATE** button.
- Click on "**click here**".
- Fill in your name, address, and credit card information (all the places marked with "\*"). Don't worry, this is a *secure* website, so your information is safe.
- Click the blue **Continue** button at the bottom to confirm your donation.

That's it! You don't have to "log in" to anything.

You can also use this same website to credit your donation to a specific Walk team or an individual team member. You'll be hearing more about that soon!

## 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.*

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

*Thank you!*





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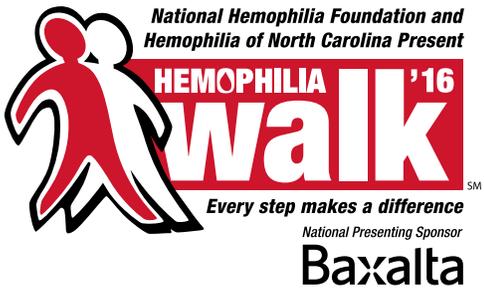
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[www.hemophilia.org/walk](http://www.hemophilia.org/walk)