

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2016

Get Your Walking Shoes Ready - 2nd Charlotte Walk on April 16

If you've always wanted to walk around and enjoy Charlotte in the springtime, now's your chance! This year HNC's Charlotte Hemophilia Walk will begin in front of BB&T Ballpark in Uptown Charlotte with a 5K route that will take us around Bank of America Stadium – home of the Panthers. It will be a wonderful way to enjoy friends, family and other supporters as we stroll along the streets together in the midst of two of Charlotte's premier athletic venues!



Not only is this a chance to join the largest gathering of members in the Charlotte area, but also a wonderful opportunity to bring your friends, family and 4-legged companions out for some fun! You will

Continued on page 17



The Unsung Hero

Since 2007 HNC has been awarding an annual Volunteer of the Year Award to someone who has dedicated her or his time and talents to the organization throughout the year. Over the years we have had many



deserving couples and individuals who have been recognized for their efforts. These folks have continued to do great work for the organization, for which we are extremely grateful. This year we wanted to honor a man who many people may see at events but may not recognize all he does and has done behind the scenes for HNC. That man is Charles Register.

Charles was presented with the Unsung Hero Award at a special surprise dinner with friends. What is an unsung hero? *They're that someone who keeps it all going, who is calm under fire, who may be behind the scenes but is always there when you need them.* For anyone who knows Charles, this description couldn't be more perfect.

Continued on page 4

Save The Date

HNC "Hearts for Hemophilia" Casino Night
Charlotte, NC
January 30, 2016

HFA Symposium
Las Vegas, NV
March 31 – April 2, 2016

NHF Washington Days
Washington, DC
February 24-26, 2016

HNC Legislative Day
Raleigh, NC
First Quarter, 2016

Charlotte Hemophilia Walk
Charlotte, NC
April 16, 2016

World Hemophilia Day
April 17, 2016

NOW Conference
Phoenix, AZ
April 22-24, 2016

HNC Annual Meeting
Greensboro, NC
May 14, 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
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 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

University of North Carolina At Chapel Hill School of Medicine

Campus Box 7016
Physician Office Building
170 Manning Drive
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

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www.inalex.com

LA Kelley Communications

1-978-352-7657
www.kelleycom.com

Patient Notification System

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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 of North Carolina, a member of the NC Center for Nonprofits.



From the HNC Office

It's that time to reflect on all we've accomplished in 2015 and look to the future as we come into a new exciting year. In 2015, HNC hired new staff including Jamie Strom-Administrative Coordinator & Bookkeeper, Gillian Schultz – Program Manager, and Karyn Davis – Manager of Operations. With the help of the new staff, HNC has been able to offer more to our members.

We had amazing events and programs throughout the year that have met the varying needs of our community. HNC held our first Charlotte Walk, which combined with the Raleigh Walk surpassed our all of our expectations! We were able to expand the programming at the Annual Meeting and Family Retreat to include childcare for all children. Most recently, the entire HNC staff and

board of directors joined the community at the annual Holiday Celebration. Together, we enjoyed a day of fun mixed with some brainstorming about how we can continue to strengthen HNC as an organization through 2016 and beyond.

As we enter into 2016, we are looking forward to the expansion of our programming including the HOPE and SOAR programs, increasing our outreach across the state so that all members, no matter where they are located can feel like part of the organization, and further development of the HNC board. As we move forward to reach these goals, we encourage your input and support.

Happy NewYear!



Mail Containing Information on Products and Services (*Future 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 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).



Board Member Spotlight: *Why I Serve*

By: Leroy Taylor

I first joined the HNC board to give to others what HNC has given to me. I had no idea what severe Hemophilia A was. Being a somewhat new parent of an 18 month old child diagnosed with severe Hemophilia A, I had no clue on what to do much less how my wife and

I were going to raise a child with this bleeding disorder. I was introduced to HNC and they have been with me all the way. My son is now in his freshman year of college.

Five years later, my daughter comes along and we thought, "ok a girl, we dodged that bullet!" We discovered she had von

Willebrand Disease. HNC was there for us to turn to and help educate us on these disorders. She now plays on her middle school basketball team. Through it all HNC has been behind us, beside us, and sometimes in front to guide us. They helped me become a better parent.

When I was asked to serve I proudly agreed. I continue to serve on the board to help bring awareness to outside of the hemophilia community and to educate the new parents of children diagnosed with bleeding disorders. I would like to share what HNC taught me. "You control your bleeding disorder, you don't let the bleeding disorder control you."

Unsung Hero *continued from page 1*

Charles began his volunteer career at birth when he was diagnosed with severe Factor VIII deficiency. Since then, he has gone on to accomplish so much in order to make him the extraordinary person he is today. Charles and his wife, Kathy, have truly dedicated their time and talents to HNC and the entire bleeding disorders community, from board members and key volunteers to interim Executive Directors of the organization!

Without Charles' endless hours of guidance and expertise, HNC would not look as good as it does – literally! Charles has donated many hours of his time and lent his skills in a variety of areas including web site design, logo and publications design, and computer guidance for us “not-so-techy” individuals!

HNC has made great strides over the past year in the programs and services we offer. This is due, in large part, to Charles' contributions and tireless efforts in meeting our goal to assist the bleeding disorders community in North Carolina. Thank you Charles and congratulations on being named HNC's Unsung Hero.

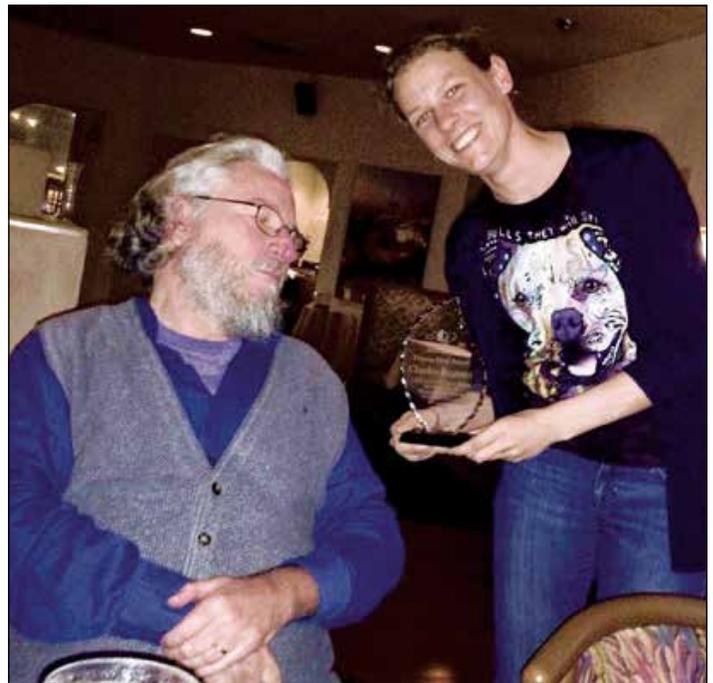
Here are quotes from a few of the many people that Charles has impacted:

“Charlie made a personal impact in my life as a kid learning how to self infuse, I remember him as the first person I ever saw infuse at home. Since then he has made a positive impact on every person living in NC with a bleeding disorder through his work with HNC. The dedication he has shown to our organization has inspired me and others to eternally give back to our community.” – *Matt Igelman*

“I have known Charles (Charlie) and Kathy since the 1970s. My earliest memory of them is a visit I paid to Charlie who was in the hospital. I walked into his room and found the two of them happily playing baroque and early music on the recorder. A casual observer would have no idea of just how serious hemophilia (with an inhibitor) can be. Charles & Kathy had discovered early in life the value of singing their way through life.

During the formative years of what was to become Hemophilia of North Carolina, Charles (& Kathy) also demonstrated an early commitment to serving their way through life. After I withdrew from active service in HNC, it was Charles (& Kathy) who kept the torch burning and kept continuity going for the community for years. They were never interested in grabbing the spotlight. They were happy to serve in the background.

From where I sit, Charlie's life, while affected by hemophilia, has really been about singing, service, family, integrity, intelligence and, of course, good beer. It is time for us all to hear the music of Charlie's life, and perhaps to raise our voice in a rousing chorus of “For he's a Charlie good fellow...” – *George McCoy*

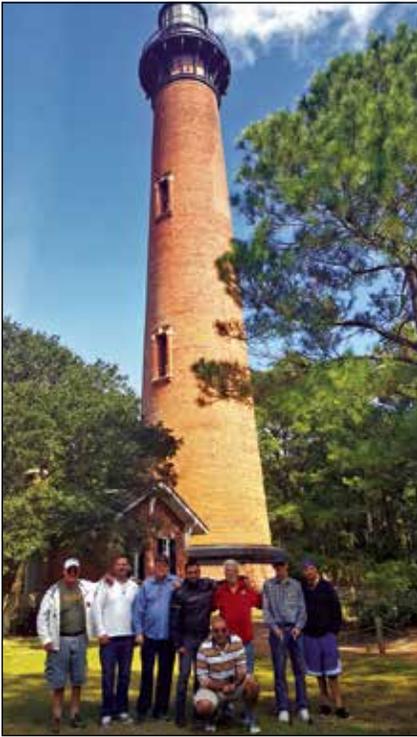


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Blood Brotherhood Retreat



Who doesn't want a long beach weekend at a fantastic house equipped with a pool table, ocean view, swimming pool, and more?! Not to mention having fellow Blood Brothers there to share the experience. From October 22-25, adult men with bleeding disorders from across the state met in Corolla, NC, to learn from one another, relax and possibly get a tan! Between the mouthwatering cookout and a visit to the lighthouse, all the Blood Brothers went home with a smile and some new stories to remember the weekend. We look forward to the 2016 Blood Brotherhood Retreat and hope you'll join us!



HNC Community Yard Sale

October 24

HNC held its second annual Yard Sale fundraiser in October and it was even more successful than the first! We raised over \$750 (more than double the funds from last year's) and continued to build awareness about HNC and the bleeding disorders community. As an added benefit, those who were able to donate items to sell now have a little less clutter around the house! We are always grateful for those who support our events and programs, and this time is no different; so we want to thank all who contributed items and other assistance to make this year's Yard Sale such a success.

The Yard Sale was overflowing with items: clothing, jewelry, cookware, dishware, DVDs, electronics, home décor, books, puzzles, toys, games and more. It was a warm and sunny day. The customers couldn't wait until the start time of 8:00am and started to arrive closer to 7:30. Besides looking for a great bargain, there were customers that asked questions about HNC and seemed interested in understanding more about bleeding disorders. We even had some repeat customers from last year, so we hope that they will be on the lookout and support us again next year in 2016!

You may be asking what you can do to participate in next year's HNC community yard sale. The first step is to collect those household and clothing items that your family outgrows or no longer uses. The next step is to save those items; plan to either donate them to the yard sale here at the HNC office, or have your own yard sale and donate the proceeds to HNC.

The 2016 HNC yard sale will take place on October 22, 2016! If you wish to participate in HNC's Yard Sale or get more information about how to host one of your own on the same day, please contact HNC staff toll free at 800-990-5557.



\$109,500 Raised for 8th Annual Raleigh Walk!

October 17th was another gorgeous day at Lake Crabtree County Park in Morrisville for the *8th Annual Raleigh Hemophilia Walk!* With more than 800 people and 30+ dogs in attendance, we celebrated and honored our community while surpassing our \$100,000 goal. This is Hemophilia of North Carolina's (HNC) largest fundraiser and awareness-raising effort and we're proud to say that 100% of the money stays local and is used for the many HNC programs and services offered throughout the year!

When the National Hemophilia Foundation (NHF) asked us in 2008 to be one of five first-time Hemophilia Walk sites through their new fundraising initiative, we didn't know how it would turn out. For eight wonderful years, HNC has surpassed our goals thanks to our members, donors, and corporate support. This is also the largest gathering for community members and provides an opportunity to spend three fun-filled hours meeting and connecting with others.

The three-hour event flew by, with no shortage of stuff to do! Sweet Tomatoes came out in great spirits with a delicious and donated

breakfast for all. As they've done for years, Starbucks donated coffee to get the event rolling and keep everybody warm. PetMania donated 100 doggie bags, with plenty of treats and other goodies, which went quicker than ever! Other familiar faces were there too. Jecoreiography brought their A-game and got the whole crowd dancing, while DJ Kevin McVerry pumped up the volume. The Carolina Hurricanes brought out the Slap Shot Booth again. Their mascot, Stormy, brought his dance moves like Jecoreiography and helped kick off the walk when it was time, along with the NC State cheerleaders. Miller Motte donated their time to come out again this year providing free massages to all, and the line never stopped! Our National and Gold Sponsors in attendance brought out other fun activities and treats for all to enjoy. Once the walk concluded, Jimmy John's supplied their well-known subs and some tasty pickles for the side.



The Walk was not only filled with activities, but awards and raffles too! Once again we awarded the King, Queen, and Jr. Droplet awards to three people who went above and beyond. Congratulations to this year's recipients Troy Schoolcraft (Team Schooly), Ashley Emory (Out4Blood), and Liam Fentress (Team Liam). The UNC Tarhealers took home the esteemed Hospital Cup for the 8th consecutive year. Their extraordinary efforts were not unnoticed as they also placed third on the Top Teams list with over \$5,300 raised. Biogen also blew it out of the water by raising \$11,600 within their local facility in Morrisville. The Clot Hoppers took home the top non-industry team award, by hopping to the second position on the Top Teams list, with an impressive \$6,300 raised! Grifols, who also has a local facility, went home with smiles on their faces as their



Raleigh Walk! *continued from page 6*

team brought out the most supporters with over 100 people in attendance. A lucky winner from team Jaden's Jewels & Jaden's Gents took home the Vendor Visit Raffle grand prize, a GoPro HERO4 with an accompanying drone for extra fun! Lastly, a very adorable child in attendance won a Carolina Hurricanes hockey stick, signed by #53 Jeff Skinner.



We're only as strong as our community and the Walk continues to show just how united we are. Each year, HNC raises the bar, both within our organization and with others across the country, and we're



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extremely proud of our accomplishments. None of this would be possible without the dedicated membership, supporters and sponsors. From the bottom of our hearts we thank you. Join us in Charlotte for our 2nd Annual Charlotte Walk on April 16th and the 9th Annual Raleigh Walk on October 15, 2016! We can't wait to walk with you again!

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Save One Life came to Durham

We were so proud to have Save One Life, an amazing organization, in our backyard on October 22nd! Save One Life is an international nonprofit organization that offers individuals, families, companies and/or organizations the opportunity to **sponsor a child or adult with a bleeding disorder** in a developing country.



“Hearts at Home” was a great event that allowed attendees to see the impact of their donations and sponsorship of children through the organization. We played a game that helped put into perspective the daily struggles that people with bleeding disorders across the globe have to cope with and it was truly eye-

opening. We are so fortunate in the US to have the access to treatment and care that we do. The evening was a great reminder of this fact.

As many of you know, we ask for your support in donating to the Save One Life organization at various events. For years, we’ve collected toothbrushes and toothpaste at the Holiday Celebration and included sponsoring a child as an auction item at the Casino Night fundraiser, which is donated to Save One Life. At this years Family Retreat, we made first aid kits to send as well. We also encourage you to consider sending ProjectSHARE any unexpired factor that you do not plan to use as they will find it a good home. Give Save One Life a call and see how you can make an impact!



Tarhealers team takes home the Hospital Cup

On December 10th, HNC staff joined the UNC Tarhealers for a celebratory lunch to thank them for all of their hard work and dedication to the 8th Annual Raleigh Hemophilia Walk. We also had a chance to tour the new UNC HTC offices. Since 2008, the UNC

Tarhealers have brought home the Hospital Cup, which is awarded at the Raleigh Walk to the hospital team that raises the most funds. Congratulations to the UNCTarhealer team on another victory and for all you do for the bleeding disorders community!



Friday with Friends

HNC held a roundtable dinner for the Latin Union Program on November 13 at Something Different restaurant in Asheboro. It was a great evening with lots of friends and even a birthday celebration for one of our members! We talked about the upcoming events and what's been going on. After a delicious meal and some dessert, everyone headed to the local IMAX to enjoy a movie. It was a fun Friday evening with friends! As we move forward with 2016, we look forward to many more great memories with the HNC Latin Union Program!



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Family Retreat

The 2015 Annual Family Retreat was a huge success! This year the retreat moved across the state from the beach to the mountains. The event was held from Friday, November 20 – Sunday, November 22 at Lake Junaluska Conference and Retreat Center west of Asheville. The new venue was beautiful, with recently updated modern accommodations. As the season was changing from fall to winter, they had begun decorating for the holidays, making it appear a festive winter lodge.

On Friday evening, after a welcome session, orientation and dinner, families participated in a fun carnival. There were games including Minute to Win It, putt-putt, bowling, soccer, cups, and marble racing; as well as fresh popped popcorn and a photo booth filled with great props for fun family pictures to remember the evening.

Saturday's sessions included an adult track and a children's track. The children's track was split into groups by whether the child is affected with a bleeding disorder or if they are a sibling or child of someone with a bleeding disorder. Children who have a bleeding disorder learned the basics about their bleeding disorder and about how their body works in the program, *My Factor, My Body*, a Baxalta Hello Talks program given by Patricia Espinosa-Thomson. Later in the morning, these kids learned about activities they could safely participate in through the program, *Playing it Safe*, which was led by Grant Hiura, National Hemophilia Foundation (NHF), Kevin Young and Shelby Green, each of the NHF NYLI program for young adults in the community. The kids were able to talk about different activities and sports that they could participate in and they got to move around and be active. Children who are not affected took part in a *Sibling Art Project* run by Grant Hiura (NHF), Kevin Young (NYLI) and Shelby Green (NYLI); and they learned about what makes them and their sibling (or parent) with a bleeding disorder special. Daycare was provided for children under 5 for the entire weekend.

The adult track on Saturday morning included the presentation, *Bleeding Disorders 101, the Clot that Binds Me* led by Gina Raymond from CSL Behring. Adults also learned about the genetics and basics of hemophilia and von Willebrand Disease. They later heard the presentation *When to Freak Out, and When to Calmly Pick Up the Phone* led by Sue Geraghty, RN, representing Hemophilia Federation of America (HFA). Parents were taken through all stages of life and situations that are normal and situations where you might need to call your treatment team, or even just another parent in a similar situation.

Mary Ann Massolio, an active athlete and woman with vWD spoke to everyone during lunch about being active and having their kids be active in life. After lunch, she led a fun and interactive session with all of the kids where they played games and learned about the importance of physical activity in maintaining a healthy body. The adults heard a presentation, *Consumer Rights and Responsibilities*, led by Grant Hiura, NHF, which laid out a variety of different situations that could occur and how to handle them. Later, adults put together first aid kits to be donated to Save One Life. These first aid kits will help people in developing countries with bleeding disorders.

After these sessions and some free time, there was *Game Night* on Saturday night, led by Sonji Wilkes and sponsored by HFA. There were bleeding disorder specific games such as Jenga, where you had to answer questions about a bleeding disorder, as well as Jeopardy, Are You Smarter than a 5th Grader and more! There was even one incredibly long game of Uno that lasted over an hour!

On Sunday, the final day of programming, the children learned about blood thanks to a program from High Touch, High Tech. As part of this program, children did three experiments and even made their own blood! Later in the morning they listened to a Hello Talks presentation, *Bullying*, led by Karli Johnson from Baxalta that taught



Family Retreat continued from page 10



different ways to handle situations where they could encounter bullying. They then role-played a variety of different situations.

The adults' final workshop, *Self Infusion at Home*, led by Sue Geraghty, RN, HFA, went over all the different ways to be infused as well as both the positives and challenges of home infusion. The highlight of the weekend was at the end of the infusion session where everyone

got to see the Vein Viewer that was donated to HFA. Many parents talked about how every doctor's office and emergency room should have one as it allowed us to see the veins that are sometimes so difficult to find!

There were several opportunities over the weekend to visit with our event sponsors. The weekend would not have been possible without the support of sponsors including Baxalta, Bayer, Biogen, CSL Behring, Emergent Bio Solutions, and Novo Nordisk as well as the support of our national organizations, the National Hemophilia Foundation and Hemophilia Federation of America.

At the end, adults and children said goodbye to friends old and new and many left talking about the fun and educational weekend they had.

HNC is looking forward to next year's Family Retreat that will be held again in Lake Junaluska! **SAVE THE DATE: September 30-October 2, 2016 and stay tuned for details!**



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Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2015 HNC Family Retreat:

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HNC Holiday Celebration at Castle McCulloch in Jamestown, NC

There is no better way to begin the holiday season than the annual HNC Holiday Celebration! On December 5th, HNC members gathered to mark the end of a great year while enjoying some wonderful food and friends! The enchanting atmosphere of the Crystal Garden Ballroom of Castle McCulloch complimented the theme of the event, “Winter Wonderland at the Castle & Giving Back”.

Those in attendance were inspired by the words of Anita Smith, PNP, our guest speaker and Hemophilia Nurse Practitioner at Wake Forest University’s HTC, through her presentation entitled



Resilience. Charlene and Gillian were able to review some of HNC’s memorable events from 2015 and announced what we can all look forward to from HNC in the coming weeks and months. Additionally, in lieu of a 2015 Volunteer of the Year Award, Charles Register was recognized at the Celebration (though he could not be there in person) with the HNC Unsung Hero Award for his work and dedication benefiting the organization since its beginnings over

40 years ago. Also, in the spirit of Giving Back, attendees showed their support of the Save One Life organization by bringing donations of toothbrushes and toothpaste to be provided to bleeding disorders community members around the world.

After a delicious meal, attendees got to know each other better through a game of “Human Bingo”. In this game, players tried to match the descriptions in the Bingo sheet boxes with the people they met until they got five in a row or BINGO! This was a fun way for people to stretch their legs and learn more about fellow HNC members.

Finally, to the excitement of children of all ages, we had a visit from Santa & Mrs. Claus making every child’s afternoon complete with a memorable picture, storytelling and even a holiday gift! Though the weather was sunny and mild, the event was truly a Winter Wonderland at the Castle. We look forward to seeing everyone back here for the 2016 Holiday Celebration on December 3rd!



Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2015 HNC Holiday Celebration:

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Viernes con amigos

HNC organizó un programa en mesa redonda para miembros de la Unión Latina el día 13 de Noviembre en el restaurante “Algo Diferente” en Asheboro. Fue una gran noche con muchos amigos reunidos y hasta una fiesta de cumpleaños para uno de nuestros miembros! Hablamos sobre los próximos eventos y lo que ha estado sucediendo.



Después de una deliciosa comida y algún postre, todos se dirigieron al IMAX local a disfrutar de una película! Fue una divertida noche del viernes con amigos!

Información sobre los campamentos

Los campamentos tienen muchos beneficios para los niños, especialmente para aquellos con un trastorno hemorrágico. Pueden ayudar a un niño a ser más independiente, aprender más sobre los trastornos hemorrágicos y aprender cómo tomar el control de su vida en vez de que el trastorno hemorrágico controle la vida del niño. El campamento es una oportunidad para que los niños puedan compartir y aprender de otros que enfrentan desafíos similares.

La mayoría de los campamentos de verano para las personas jóvenes con trastornos hemorrágicos tienen una meta en común: ofrecer a los niños una experiencia representativa de un campamento, un lugar donde se trata a todos de la misma manera y donde se hace énfasis en las posibilidades, no en las limitaciones. Sin

embargo, difieren en la forma como se logra esa meta. Algunos se enfocan en apoyo y educación de la salud; otros tienen la filosofía de dejar a los niños ser niños y no mencionan los temas de infusión, autosuficiencia o asuntos más fuertes como prepararse para una carrera y obtener un seguro médico.

Source: www.stepsforliving.hemophilia.org



Planificación para 2016

Mientras miramos al 2016, estamos muy contentos de tener más personal para ayudar a continuar con nuestra labor. Dicho esto, necesitamos su ayuda. El programa de la Unión Latina ha sido una parte importante de nuestra Asociación durante años. Queremos seguir mejorando nuestros esfuerzos para que tenga el apoyo que necesita. Hay muchas maneras

que usted puede involucrarse más: participando en eventos, escribiendo artículos para el periódico, traduciendo, y colaborar con nosotros para organizar un evento cerca de usted y mucho más. Por favor déjenos saber si usted cuenta con el tiempo para hacer del 2016 un año mejor!

NC School Nurse Conference

HNC was honored to be a representative at the 32nd Annual NC School Nurse Conference at the Joseph S. Koury Convention Center in Greensboro, NC, on October 15-16, 2015. This premier conference reaches over 500 school nurses annually. It is also an important opportunity for HNC to connect with the school nurse community while developing awareness of bleeding disorders with some of the most important people at our children's schools regarding their health and safety.

The information handed out to our school nurses included materials describing signs and symptoms of bleeding disorders, contact information for North Carolina's Hemophilia Treatment Centers, contact information for Hemophilia of North Carolina, awareness flyers that may be hung in health rooms or bathrooms and a book on von Willebrand Disease written by Dr. Andra James.

While all of the nurses were familiar with hemophilia, many were not as informed when it came to von Willebrand Disease. The shared information was very well received, and the nurses were grateful to have increased their knowledge of bleeding disorders. The student nurses present at the conference were particularly interested in learning more about bleeding disorders, especially von Willebrand's, as well as learning about the role of HNC in our state. Several nurses were interested in setting up in-services on bleeding disorders at their schools, and the HNC office has received requests for more information on bleeding disorders since the conference.

A well-educated school nurse may be one of the first to notice the signs and symptoms of a child's bleeding

disorder, especially in teen girls. It is our hope that by reaching out and sharing information at this conference, we have better prepared them to do so. Thank you to CSL Behring for helping to make this opportunity possible!

Women's Night Out

Hemophilia of North Carolina partnered with CSL Behring on a fun Women's Night Out dinner on December 15 at Harper's Restaurant in Pineville! This social and educational event was for any woman who has a bleeding disorder or cares for someone with a bleeding disorder.

The evening started out with a social hour. Women mingled, shared stories and caught up with friends new and old. After the social hour, everyone enjoyed a delicious dinner. Sharon Ingram sang the SOAR song which includes lyrics to the melody of "I Am Woman" by Helen Reddy. Lori Kunkel then presented the Common Factors program "Laughing Through Your Stress." She shared several personal stories of times when her family faced stressful situations. They were able to get through those times because they were able to laugh. She emphasized the importance of laughing every day and how it can help to ease a stressful situation. After dessert, the women played a fun game of Ball 'O Saran Wrap – where the women had to unwrap a large ball made of only saran wrap. Inside they found candy and gifts.

After a fun evening, the women said their goodbyes and hopefully felt a little less stressed during the busy holiday season!

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

How to Stop Saying Yes When You Want to Say No

By: Chantalle Gerber

“Live your life for you not for anyone else. Don’t let the fear of being judged, rejected or disliked stop you from being yourself” ~Sonya Parker

I am a sucker for saying yes. Sometimes I even find myself thinking “no, no, no, no” and then I blurt out “yes.” Why is it so difficult to say the word “no”? It’s just a word, right?

After feeling trapped for some time by my excessive urge to be agreeable, it got me thinking. I asked myself why it was so important for me to please everyone, to the point that I would feel resentful and stressed because of it. I realized I was afraid of saying no because my biggest fear is rejection. I was afraid that every time I did this, I would disappoint someone, make them angry, hurt their feelings, or appear unkind or rude. Having people think negatively of me is the ultimate rejection. Whether they say what they think of me, out loud or not, does not matter to me. It is the thought that they look down on me. And so I realized exactly why I found it so difficult to say no. I realize this is not just a challenge that I face, but one that many people go through every day. It’s a heavy burden to carry because with the urge to say yes also comes a lack of self-confidence and self-value. If, like me, you’re having trouble saying no, this may help.

Saying No Doesn’t Mean You’re a Bad Person

Saying no doesn’t mean that you are being rude, selfish, or unkind. These are all unhelpful beliefs that make it hard to say no. Learning where these beliefs have come from is a great way to learn to let go of them. Did you ever wonder why it was so easy to say no when you were a little kid and why it has become so difficult now? What happened?

Well, as a child, we learned that saying no was impolite or inappropriate.

If you said no to your mum, dad, teacher, uncle, grandparents, and so on, you were most certainly considered to be being rude, and you would have probably been told off for it.

Saying no was off limits, and yes was the polite and likable thing to say.

Now that we are all adults, we are more mature and capable of making our own choices, as well as knowing the difference between wrong and right. Therefore, no shouldn’t be an off limits word, but rather something that we decide on ourselves, based on our own discretion.

But sadly, we hold onto our childhood beliefs and we continue to associate no with being dislikeable, bad mannered, unkind, or selfish. We worry that if we say no, we will feel humiliated, guilty, or ashamed, and will end up being alone, rejected, or abandoned.

Knowing Your Value

The second step to learning to say no is realizing that you are valuable, and choosing your own opinion about yourself over others.

I have learned that if you live your life depending on other people’s approval, you will never feel free and truly happy.

If you depend on other people’s approval, what you are basically saying is “Their opinion of me is more important than my opinion about myself.”

If you’re opinion of yourself is actually quite low, remember that:

- Your problems do not define you.
- It’s okay to make mistakes—nobody is perfect, and everybody does things that they regret; this is what makes us human.
- What makes a person great is not their looks or achievements, but their willingness to love others, be humble, and grow as a person.
- You are unique, valuable, and important. No one else in this world can offer what you can.

Is It Really Worth it?

The third step to learning to say no is deciding if saying yes is really worth it.

After committing to something, doubt eventually sets in and you may begin to think of ways you can get out of it. And if you don’t have any good excuses, you then have to decide if you are going to tell the truth or come up with a lie. Think about the anguish, stress, and resentment that saying yes has caused you. Wouldn’t it be so much easier and straightforward to just say no in the first place?

I remember this one time that I said yes to something and then later felt so bad about it that I ended up lying my way out of it. I still feel bad that I lied.

My boss called me one day and was asked if I could work the following Saturday. As usual, I blurted out a polite “Yes, of course, that’s no problem at all.” I actually had plans with my boyfriend, which I was really looking forward to.

Later, I found myself feeling absolutely terrible about having said yes and I wished that I had just had the guts to say no from the beginning.

Continued on page 16

How to Stop Saying Yes

Continued from page 15

Dreading the idea of having to work that day, I called my boss back with the best excuse I could think of. I told her that I had completely forgotten that it was my dad's birthday that Saturday and that we had a family get-together (which was certainly not the case).

Looking back, I realize that it really isn't worth it to say yes when you don't want to. I have a right to say no and shouldn't be afraid of letting other people down at the cost of my own happiness.

If you have also decided that it's worth it to you, and want to learn to say no, try these simple yet effective tips for doing so with confidence.

Helpful Tips for Saying No

- Be direct, such as "no, I can't" or "no, I don't want to."
- Don't apologize and give all sorts of reasons.
- Don't lie. Lying will most likely lead to guilt—and remember, this is what you are trying to avoid feeling.
- Remember that it is better to say no now than be resentful later.
- Be polite, such as "Thanks for asking."

- Practice saying no. Imagine a scenario and then practice saying no either by yourself or with a friend. This will get you feeling a lot more comfortable with saying no.
- Don't say "I'll think about it" if you don't want to do it. This will just prolong the situation and make you feel even more stressed.
- Remember that your self-worth does not depend on how much you do for other people.

Learning to say no has been one of the best things I have done for myself. Not only has it challenged me to overcome my fear of rejection, it has helped me to feel in control. I don't feel trapped, resentful, or guilty anymore. Instead, I feel empowered and free. If you want that same feeling of freedom and empowerment, then take control, challenge yourself, and learn to say no.

Chantalle Gerber is a writer and co-founder of Want2discover. Visit her website for more great articles on self-improvement and how to live a fulfilling and happy life. Be sure to download a copy of her Free Ebook: 52 Simple Steps Towards Happiness and Success. This post was republished with permission from tinybuddha.com. You can find the original post here: <http://tinybuddha.com/blog/stop-saying-yes-want-say-no/>

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C O A G U L A T I O N

Heritage
At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

Community
We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

Innovation
As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.

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HNC Charlotte Walk *continued from page 1*

be amazed at all there is to do. From photo booths to hands-on activities, there is something for everyone to enjoy. You won't go hungry either!

This is our 2nd Annual Walk fundraiser in Charlotte so we're excited to grow this awesome event thanks to the support of members, friends and family, and our sponsors! Members had been asking for a Walk in Charlotte for years and we were so thrilled to see hundreds of people come out last year. We want to make this year bigger and better so please reach out to the office and let us know how you can help!

Info will be available at www.hemophilia-nc.org to help you kick start your team! The site features information for sponsors, teams and volunteers. Printed Sponsorship and Team Captain Packets are also available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. Call your teammates, grab your walking shoes and join us in Charlotte on April 16th!

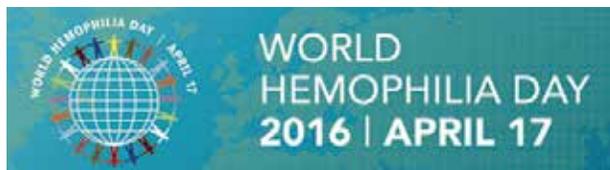


Upcoming Events

HNC Casino Night

January 30, 2016
Charlotte, NC

Mark your calendar for the 9th Annual “Hearts for Hemophilia” Casino Night on January 30, 2016, at Big Chill in Charlotte! This is a lively event with food, a silent auction, casino games and music. It’s sure to be an entertaining night for all who attend. If you know someone that might want to support the event through an auction or raffle item or by sponsoring the event, we are always looking for new partnerships! To purchase tickets and learn more information about this year’s Casino Night, please visit the HNC website or give us a call!



What’s in store for World Hemophilia Day 2016?

April 17, 2016

World Hemophilia Day takes place annually on April 17th as a day of awareness for hemophilia and all bleeding disorders. 2016 marks the 28th annual World Hemophilia Day! The theme this year is: Treatment for All, The Vision for All. *Globally, 1 in 1,000 people has a bleeding disorder. Most are not diagnosed and do not receive treatment. The purpose of World Hemophilia Day is to provide an opportunity to talk to your family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder. Together we can change that!*

Last year, Hemophilia of North Carolina (HNC) partnered with Biogen to host a very memorable World Hemophilia Day (WHD) event. As one of 17 sites across the world, HNC was proud to watch as the Wells Fargo Duke Energy Building in downtown Charlotte was lit up red in honor of World Hemophilia Day! The entire event included a dinner with presentations about the spirit of the day and its impact worldwide and an inspirational video to put into perspective how we shouldn’t forget that there are people living all over the world with bleeding disorders, many of whom do not have access to proper treatment or care.

So, what does HNC have in store for World Hemophilia Day 2016? Stay tuned to find out and save the date!



Upcoming Events Continued on page 19

Upcoming Events *continued from page 18*

HNC Annual Meeting: Don't Miss It!
Save The Date: 43rd Annual Meeting of the Membership

May 14, 2016
 Sheraton Greensboro Hotel



While HNC hosts a variety of programs and retreats throughout the year, there is nothing like the Annual Meeting. This is our largest one-day event that combines the entire range of individual programming that we do annually. From the expert speakers to the knowledgeable medical professionals, there is always important news and information regarding the bleeding disorders community. Whether you are comfortable talking in large or small groups, we have breakout sessions for: families, men, women, Latino/a individuals, and spouses/partners. It's an opportunity to hear from us and from fellow community members about what is going on in the world of bleeding disorders. You'll have an opportunity to meet pharmaceutical and home care companies that support the community. We offer childcare for all ages, including a special teen track. This is your chance to make your personal mark on HNC's future by voting on our Board of Directors nominees, which is presented to the membership annually at this meeting. Save the date and join us!

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Stay Tuned for More to Come! !

HNC has been busy with many events over the past few months, and we plan to continue these happenings through 2016. Stay tuned for information on educational dinners and other social events being held over the next few months. Watch the HNC website, Facebook page, and information coming via email and snail mail for events and information. Some other programs that you will see include Blood Brotherhood events for men affected with a bleeding disorder, Latin Union events with programs geared towards our Spanish speaking community, as well as an increase in our HOPE programming for families with young children who have a bleeding disorder and SOAR programming for women affected by a bleeding disorder.

If you are interested in seeing a program come to you, or have any requests for specific programs, please let us know! You can call the HNC office, (800) 990-5557 or email us at info@hemophilia-nc.org.



**Summer Camps – Applications are available now for the following summer camps!
Please follow instructions listed for each camp to access applications.**

Victory Junction Camp in Randleman, NC

Victory Junction is a year-round camping facility that serves children, ages 6 to 16, with chronic medical conditions or serious illnesses, at no cost to their families. During the summer, Victory Junction offers disease-specific sessions for up to 128 children per session. During the fall, winter and spring, family weekends are offered to up to 32 families per weekend - check out their website for all the Family Weekend camp themes they offer throughout the year! For more information, go to www.victoryjunction.org or call 336-498-9055.

**June 12 - 16, 2016 (Sunday-Thursday):
Bleeding Disorders/Sickle Cell Week**

Complete and online application using this link:
<http://victoryjunction.org/application-cz/>

Please remember that this is an application process and acceptance is not guaranteed due to the limited number of campers per session. Please call Victory Junction directly with questions at 336-498-9055.

Camp Carefree in Stokesdale, NC

Since 1986, Camp Carefree has provided a free, one-week camping experience for kids with bleeding disorders. Camp Carefree provides the needed freedom to play, learn, and have fun with others who encounter similar difficulties. The program

also includes camps for well siblings who live with a chronically ill sibling (Sibling Camp) and for well children with a seriously ill or disabled parent (Kids Camp). For more information, go to www.campcarefree.org, email 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, Arapahoe, NC

Camp Rainbow is a week-long summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Camping experience goals include: building self-confidence and independence, emotional and social development and well being, and learning and sharing support with others who are living with a chronic blood disorder. For more information, please call the ECU Hemophilia Treatment Center at (252)744-4676 or visit their website at <http://www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm>.

June 2016: Camp Week TBD



2015 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2015. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

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Thank You 

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We thank our sponsors for their continued support of the community.

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HOPE Update

- Help
- Opportunity
- Partnership
- Empowerment

What is the HOPE Program? HOPE is an HNC program for families with a child from birth to age 12 with a bleeding disorder. HOPE stands for Help, Opportunity, Partnership, Empowerment. Just think of how much a child's life changes in just a few short years. No one has to be alone in raising a child with a bleeding disorder. Together, with a community of other parents, we can help each other have the opportunity to go through these life stages with support, partnership and knowledge so that both parent and child can feel a sense of empowerment, 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.

Stay tuned to the HNC calendar for programs coming your way. We are planning to increase our HOPE opportunities in 2016. If you have any ideas for a program, would like a program in your area, or would like to volunteer, please call the HNC office at (800) 990-5557, or email Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org.

See you at an event soon!

Important: MedicAlert IDs

By: Gillian Schultz

I was reminded last week of the importance of having a MedicAlert bracelet. My son has worn his bracelet almost since he was born. As an infant, I used to attach it to the diaper bag but by about 6 months old, I put it on his ankle -- not to be taken off. It stayed on his ankle for probably about 3 years before his ankle got too big for it! I moved the bracelet to my son's wrist where it has stayed since then... that is until this week. When I picked him up from school, he told me it was missing. Somehow, it fell off somewhere in school. Knowing how important it is for him to have a MedicAlert bracelet, I ordered a new one right away. I am eagerly anticipating the arrival

of the new bracelet in the mail. I think it so important for our kids to have a medical ID just in case something does happen to them when they cannot speak for themselves and we can't speak for them either.

If you are worried about how plain and boring the bracelets are, you have nothing to worry about! There are so many choices from a plain chain, to fancy sports bracelets, shoe tags, dog tags, and more. The new one that my son picked out is a cool looking sports band. I just hope he keeps it on, like the last one.

Did you know that HNC can help you to get a MedicAlert bracelet and subscription to the MedicAlert Foundation service? Call the HNC office for more information at (800) 990-5557 or email info@hemophilia-nc.org.



Blood Brotherhood Update

Planning is underway for Blood Brotherhood programs in 2016, and the event schedule will be available soon. Please keep a lookout for updates on Blood Brotherhood programs as they are added to the calendar. There will be 6 events in all at locations throughout NC in order to give as many members as possible the opportunity to participate. Detailed information on these events, including dates, locations, topics and registration information, will be provided on the HNC website (www.hemophilia-nc.org) throughout the year as the events near.

As always, thanks to Hemophilia Federation of America for presenting this program and opportunity here in NC and many other states. Blood Brotherhood is a great way to for men with bleeding disorders to meet in person or online and connect with others through their shared experiences.

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.

For more information on Blood Brotherhood locally, visit the HNC website www.hemophilia-nc.org and join our Blood Brotherhood group at our future events!



NCABBD: Watchdog for Issues That Impact All

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) convened its quarterly meeting on October 9, 2015, at the HNC Morrisville office.

The NCABBD consists of consumers and Hemophilia Treatment Center staff, as well as HNC staff members, to help all parties get a better understanding of the various groups that make up North Carolina's bleeding disorder community. The group discussions can vary from meeting to meeting and usually touch on every topic that has the potential to impact the lives of those in our community – politics, money, healthcare, family, lifestyles, opportunities, employment, and more.

For those who may not know, this board is an offshoot of a mandate some years ago from the Maternal and Child Health Bureau, to keep open the lines of communication between our community and our care providers. We exchange important information to help carry out our respective missions.

After a few moments of getting settled and ready with notepads and lunches, the board began to discuss several agenda items that greatly impact our community. These discussions centered around reports from NCABBD members that included updates from HTCs around the state, HNC staffing/events/initiatives, the HNC advocacy committee update, talking about the CDC Surveillance Project, how to obtain and distribute educational materials and about the 340B Program. We appreciate the valuable conversation by those who participate in this advisory group.

The next meeting of the NCABBD will be January 8, 2016. The meetings are always lively, informative, and friendly.

Anyone interested in becoming a member of this advisory board, please contact Steve Humes at steven.humes@hemophilia-nc.org.

Thank you to the dedicated community members and experts who continue to serve on this important committee.

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GRIFOLS



Member Update-Landon Davis

By: Ashley Davis

As many of you know, our five year old son Landon had heart surgery in early November. He was diagnosed with Severe Coarctation of the Aortic Arch when he was two years old. The surgery has been put off for three years due to the severity and risks of the surgery.

Landon has Severe Hemophilia A with inhibitors. We have been fighting the inhibitors since then with Immune Tolerance and immunosuppressants, but have not been able to eradicate it. The heart defect had gotten to the point where we could not put the surgery off any longer. His arch was almost completely closed!

Our awesome team of doctors at Duke, UNC, and Boston came up with a plan to get Landon through the surgery. This particular regimen had not been used before for this particular diagnosis and surgery, so they could not say 100% if it would be successful, but they all felt very good about it.



The surgery took place on November 4th at Boston Children's Hospital and was a complete success! He had no bleeding complications and recovered remarkably! The doctors themselves were in awe of how well it went. Of course, we know God was watching over our son and guiding the doctors and surgeons. It was a complete miracle.

We can move forward now without the "what-if's" of this heart condition hanging over our heads.

What a Merry Christmas this will be! We are so blessed!

Thank you to all those who have kept up with our story and reached out to us! May God bless you all!



Latin Union Program Updates

As we look to 2016, we're excited to have more staff to help continue our work. That being said, we need your help. The Latin Union Program has been an important part of Hemophilia of North Carolina for years. We want to keep improving our efforts so that you have the support you need. There are many ways that

you can get more involved: coming to events, writing articles for the newsletter, translating, working with us to plan an event near you, and much more. Please let us know if you have time to make 2016 the best year yet!

Remembering Paul Vess, former HNC President

HNC learned that our former president, colleague, and friend, Paul Vess, died on Monday, December 14. Paul was a commanding presence in any room. He served HNC over many years in a number of roles: board member, editor of *The Concentrate*, MANN Coordinator (Men's Advocacy Network of the National Hemophilia Foundation), vice president, and then president beginning in March, 1994. Friendly and earnest, he jumped into every new office with enthusiasm and dedication. We will miss him.

Left to Right: Vivian & Paul Vess, Dale & Kathy Brisson



CDC Communications Alert: New Recommendations from the National Hemophilia Foundations' Medical and Scientific Advisory Council

HEMOPHILIA



Treatment costs for a person with an inhibitor are on average

..... **3-4 times higher**

than those without inhibitors, and can exceed

..... **\$1,000,000 a year.**






If you have hemophilia, should you be tested for an inhibitor?

Yes! According to new guidelines recently released from the National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council (MASAC), **if you have hemophilia (an inherited bleeding disorder in which the blood does not clot properly) you should be tested for inhibitors at least once every year.** Depending on the severity of your disease, and other factors that might increase your risk for developing an inhibitor, you may need to be tested even more frequently.

CDC estimates that within their lifetime, up to 1 in 5 people with hemophilia will develop an antibody (inhibitor) to the infused factor that is used to treat bleeding episodes. The inhibitor prevents the factor from working to stop bleeding and makes treatment for bleeding episodes much more difficult and expensive.

What can you do to minimize your risk for developing an inhibitor?

- You can ask your doctor about your risk for an inhibitor, how often you should be tested for inhibitors, and what you can do to help avoid developing one.
- You can participate in the Community Counts program and take

advantage of the free inhibitor testing provided as part of this CDC project. Participation in Community Counts also helps CDC understand the burden of inhibitors in the hemophilia community.

- You can participate in NHF's My Life, Our Future genotyping program. This program is important because your genotype (the specific genetic change that causes you to have hemophilia) is a very important indicator of your risk for an inhibitor. This information can help your doctor minimize your chances of developing an inhibitor.
- You can help in the identification of factors that increase the risk for developing inhibitors by participating in research studies. Once the risk factors are known, it may be possible to develop strategies to prevent inhibitors from occurring. It will take data from lots of patients in order to identify the important risk factors for inhibitors.

MASAC Recommendations

The National Hemophilia Foundation's MASAC issues recommendations and advisories on treatment, research and other general health concerns for the bleeding disorders community. Recently, the MASAC issued recommendations on inhibitor testing, the first guidelines developed on this topic. The guidelines were based on the results from the CDC's Hemophilia Inhibitor Research Study (HIRS). Through this study, HIRS investigators and CDC researchers found that people with hemophilia of all ages were at risk for developing an inhibitor and that unless people are regularly tested for an inhibitor, they can have one and not know it until the inhibitor causes a severe bleeding problem.

The inhibitor testing guidelines include recommendations on the following topics:

- Testing Frequency
- Diagnostic Method
- Monitoring and Evaluation of Testing Efforts
- Education and Awareness
- Directions for Future Research

Learn more about NHF's MASAC Recommendations.



WFH Congress and NHF Annual Meeting Announcements

2016 should prove to be an exciting year for the community as the National Hemophilia Foundation (NHF) prepares to host the World Federation of Hemophilia (WFH) Congress directly following their 68th Annual Meeting. The NHF Annual Meeting will be held from July 21 – 23, 2016 in Orlando, Florida, at the beautiful Gaylord Palms Resort & Convention Center with the WFH Congress taking place directly following from July 24 – 28, 2016 at the Orange County Convention Center also in Orlando.

While the WFH Congress takes place every two years, it has not been held in the United States for more than 20 years since individuals with HIV were banned from visiting the United States in 1987. This ban was lifted a few years ago by the Obama administration, so 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!

NHF has grants to help you and your loved ones attend the meeting. HNC also has grants so give us a call if you're interested in attending. Early registration and call for abstracts is open until January 22, 2016, for each using the following websites:

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

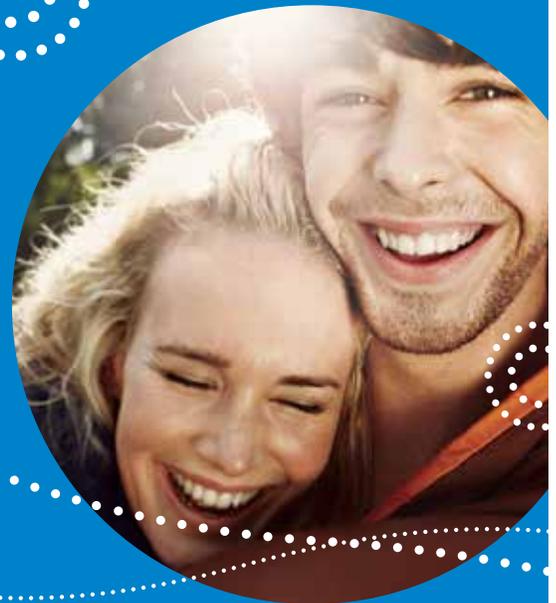
Though it is a great commitment of time and money, HNC would like to encourage each of you to explore the possibility of being part of this valuable opportunity. Call us to find out more information on how you can apply for grants to help offset some of your travel costs!



You may be eligible for a one-time, 1-month supply up to 20,000 IU of factor from Pfizer Hemophilia at no cost.

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Scan the QR code or go to PfizerHemophiliaResources.com, download the discussion guide, and bring it to your next health care provider visit.



*Terms and conditions apply. Visit www.hemophiliavillage.com for complete terms and conditions. You must be currently covered by a private (commercial) insurance plan. For questions about the Pfizer Hemophilia Trial Prescription Program, please call 1-800-710-1379 or write us at Pfizer Hemophilia Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer's RxPathways™ program at 1-888-327-7787.

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June 2014



The Journey, Celebrated

Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile.

As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.



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Fundraising IDEAS



There are lots of ways you can raise funds for HNC.

Here are just a few:

- ✓ Organize a yard sale or garage sale
- ✓ Have a bake sale
- ✓ Collect change in a donation container
- ✓ Offer a babysitting/parents' night out
- ✓ Have a spa night
- ✓ Ask for birthday donation pledges in place of gifts
- ✓ Have a game day pizza party

Donate to HNC

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

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

HOME PHONE: _____ CELL PHONE: _____

COMMENTS: _____

AMOUNT: _____

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

You may also donate online at www.hemophilia-nc.org with your credit card.

Thank you!





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