

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2015

Speaking of the Siblings

Having a child with a bleeding disorder is hard on parents. It is hard on the child with the disorder. But, what if you are an unaffected sibling of a child with a bleeding disorder? Being a sibling can be equally as hard.

There are many factors (no pun intended!) that influence how an unaffected sibling feels about having a brother or sister with a bleeding disorder. If the unaffected sibling is older, (s)he might remember a time when the bleeding disorder was not a part of the family dynamic and may sometimes wish for that time again. If the unaffected sibling is younger, or the age difference is small, either (s)he may not remember a time without the bleeding disorder or it has always been a part of life.

When you have a child with a chronic health condition, it can be easy to find yourself focusing your time and attention on that child; but it is also important not to let your other children feel left out. By incorporating your unaffected children into the routine as much as possible during the "normal" times, it should help them understand when you do need to put the focus on the affected child. When you teach your affected child about their bleeding disorder, include the unaffected sibling so they can learn together.

Bring unaffected children to doctor appointments and on hospital trips. Those visits may not always be easy, but they can help siblings to feel included. By attending doctor and hospital visits, it may also help them

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Welcome Karyn Davis, HNC Manager of Operations

I am delighted to be able to introduce myself as the new Manager of Operations at Hemophilia of North Carolina (HNC). I hope to meet and get to know many of you during upcoming events. In the meantime, I'd like to tell you a bit about myself.

After an early career in client services, I was fortunate to be able to spend several years as a stay-at-home parent. It was during those years that I developed a passion for non-profit work as a volunteer. As my children grew and I began planning my return to the workforce, I knew I had to focus my abilities to the non-profit sector. I returned to school, earned a degree in Human Services, Non-profit Administration, from Kennesaw State University in Kennesaw, Georgia, and began working as a museum Volunteer Coordinator.

Since relocating to North Carolina in 2011, I have held positions in corporate settings while searching for an opportunity to lend my enthusiasm and skills to an organization that provides meaningful support to people in the community. I believe I have found that with HNC and am thankful to be provided the opportunity to begin working with the members of the bleeding disorders community.

- Karyn

Save The Date

NHF Inhibitor Conference
Greenville, SC
October 9-11, 2015

Raleigh Hemophilia Walk
Morrisville, NC
October 17, 2015

**Blood Brotherhood
Retreat**
Outer Banks, NC
October 22-25, 2015

Save One Life event
Durham, NC
October 22, 2015

HNC Yard Sale
Morrisville, NC
October 24, 2015

HNC Latin Union event
Raleigh, NC
October 30, 2015

HNC Family Retreat
Lake Junaluska, NC
November 20-22, 2015

HNC Holiday Celebration
Jamestown, NC
December 5, 2015



*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

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www.kelleycom.com

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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

As the summer comes to an end and fall begins, we look forward to the many exciting activities that HNC has planned. We're adding staff to help fulfill the needs of the organization and to ensure we can continue to provide quality programs and services to the community. Over the last few months, we've been working to determine locations for annual events such as the Family Retreat and Holiday Celebration. In addition, we've been listening to members in order to find out what's important to them as we look to 2016. The feedback has been invaluable and we want to continue to hear from you, so if you have suggestions, please contact the HNC office.



As we move forward, it's important that we stay connected and grow together! We encourage and ask that you become involved in HNC by contributing your time, talents or resources no matter how large or how small. This connection is what built this organization in the 1970's and continues to be a viable part of what makes HNC so successful today in supporting the bleeding disorders community!

There's lots of ways to get involved and we're sure we can match your passion to a need for HNC. For instance, if you like to write; consider becoming a contributor to the newsletter. If you are a great event planner (think about how many birthday parties you've planned!); consider helping to plan the activities at the Walks (Raleigh/Charlotte). Are you passionate about sharing our story and raising awareness about bleeding disorders? Consider

being an HNC ambassador and participating in conferences and other opportunities. If you need community service hours or have special projects to complete for school credit; consider a day in the office to help with our mailings or other projects. There are many, many more examples we can share, so if you want to help but are unsure as to how, call us!

*Charlene Cowell, Executive Director
Gillian Schultz, Program Manager*

Why I Serve

By Amy Shair

Like others in our community, for years I didn't know anything about bleeding disorders. About 12 years ago I was introduced to a friend of a friend who has hemophilia. Now our families are good friends and I am serving my third term on the HNC board. That is how I was introduced to HNC, but why do I serve?

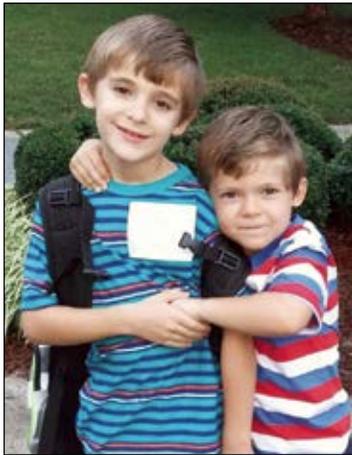
I serve because I care. I want to do what I can when I think about HNC's mission of supporting our bleeding disorder community. I serve on the board because I was asked to help. You don't get what you need until you ask! I serve because I know that HNC is a deserving organization. There are opportunities for those of us that are unaffected to support HNC members. I involve other non-affected people who support through fundraising and bringing awareness of HNC to potential new members and what I call "friends of HNC."

I decided to join the board because I have knowledge and experience that can be helpful to the board and to those affected by bleeding disorders, including family members of people who have a diagnosed bleeding disorder. I had previously served on the board of my daughter's preschool and I enjoyed the opportunity to support an organization other than being a volunteer. Being on the board allows me to use my business experience to work on HNC's future. I'm excited for what is on the horizon for HNC and appreciate the opportunity to serve all of our members.



Siblings

continued from page 1



to have a better understanding of the bleeding disorder. The nurses are likely to shower all the children with attention, bleeding disorder or not.

If you infuse at home, involve them in the infusion itself. Even at a young age, siblings can help by being a welcome distraction during the infusion, help to mix the factor, push the factor, and clean up afterwards. When you praise your child for getting an

infusion, remember to praise your children who helped too.

When the child with a bleeding disorder has a bleed, the sibling can have the job of getting an ice pack or ace bandage, giving a hug or kiss, and just being there.

In addition to involving your unaffected children during bleeds and infusions, try to keep things as “normal” as possible and treat your children equally the rest of the time. Yes, you may often remind

siblings not to hit their brother/sister, play gentle, etc. but try not to focus on that all the time. Let them go play together. Don’t let the fact that one (or more) of your children has a bleeding disorder limit their interactions together.

Even by making things as normal as you can, there will be times that your child without a bleeding disorder is going to feel left out or jealous. Don’t dismiss those feelings. Your child is likely to feel worried, may even exaggerate his/her injuries, or act up to get your attention. Even though you may be frustrated with some of those actions, try to understand how your child may be feeling. Take the time to listen to your child. If you have been going through a rough time related to the bleeding disorder, try to commit to some extra time with your unaffected child. Even if it’s just a movie together at home or a quick board game, it will help your child feel important too.

Making the bleeding disorder a normal part of the family life is key to helping siblings feel included. Of course there will be times where it is extra hard on a sibling, but if it is a “normal” part of life, siblings will have an easier time understanding. Your child may even grow up to be more compassionate than if their brother or sister did not have a bleeding disorder.

Important Note: Doing Your Part

We hope that you enjoy the programming and services that Hemophilia of North Carolina is able to provide the bleeding disorders community.

We are proud that we can offer these programs to our membership free of charge. We want for you to be able to come to an event, whether it is for education or meeting with others who are in a similar situation and we do not want the cost of attending to prevent anyone from being there.

However, these events are not free. We are grateful to our many supporters and sponsors who enable us to be able to offer this programming. Unfortunately, we have had many people who RSVP for an event and then do not attend. Of course we understand that sometimes unforeseen situations come up, whether it is a bleed or hospitalization, an illness, or something else. Please let us know if you have to cancel. Many of our events have a waiting list of people who really want to be there. Please consider the time and effort that we put into making each event a success as well as the other members who may want to be there. We want to be able to continue to offer our many programs and services to the community without having to charge a registration fee.



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Blood Brotherhood Monster Bash

On Saturday, August 8th, the NC Blood Brotherhood enjoyed a wonderful evening filled with financial tips and monster trucks! Blood Brothers from across the state met in Concord at the Embassy Suites to hear financial tips from a pro! John Cervantes of TCA Financial Group reminded the folks about some money saving tips, info on Social Security programs and how to properly prepare for retirement.



After a delicious dinner everyone was ready to see the high-flying monster trucks, so off to the dirt track at Charlotte Motor Speedway they went. Everyone dazzled as the monster trucks crushed, slammed, and raced their way



through qualifying and then enjoyed some edge of your seat racing. The evening was a great time with all the folks who came out. We thank Hemophilia Federation of America for presenting the Blood Brotherhood program here in NC; and a gracious thanks to John Cervantes from TCA Financial Group for donating his time and expertise. If you are an adult male with a bleeding disorder, join our Blood Brotherhood group here in NC. Stay tuned to the website for our upcoming Blood Brotherhood meetings.

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 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).



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Teens Travel to South Carolina for an Adventure

The Carolinas Crew was back at it again! North and South Carolina teens came together for the weekend of July 10-12 at Camp Canaan in Rock Hill, SC. Termed the “Carolinas Crew” a few years ago, this joint initiative between Hemophilia of NC and Hemophilia of SC offers teens (ages 13-18) in the community an opportunity to learn from and share with one another. Whether personally affected, the sibling, or child of someone affected, all teens are encouraged to join and to bring a friend!



that make up our community. The session was followed by activities including the pool and archery tag, which was a huge hit with everyone!

NHF came back on Sunday to lead a session entitled “Artistically Speaking”, which allowed teens to express themselves through a painting activity.

With 30 teens in attendance, Camp Canaan had plenty of space and activities to keep everyone entertained! After busing into SC and enjoying dinner, the teens played a few icebreakers, followed by a campfire and s’mores. Saturday was kicked off with some team building activities, including a low ropes course. Once they finished participating in a modified version of tag, teens shared some laughs as they were challenged to complete team activities in small groups. After lunch, staff from the National Hemophilia Foundation (NHF) came in to lead a session called “Do you bleed like me?”, where teens had an opportunity to learn from each other about the different bleeding disorders

Some of the teens chose to submit their masks, which were then displayed in the art gallery at the NHF Annual Meeting! As the retreat came to a close, teens expressed a desire to come back to Camp Canaan next year and asked for an extra day to spend with their friends. We’ve tentatively scheduled the next Teen Retreat for July 7-10, 2016 at Camp Canaan, more details will follow!



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 whom have contributed several times during this period.

Donors

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Robert Warren

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 Alice Bowen • Aimee Corriher • Doster, Post, Silverman, Foushee, Post & Patton, P.A.
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Thank You

First Ever HNC Men’s Retreat

HNC held its first ever men’s retreat at Rockfish Camp and Retreat Center in Parkton, NC, July 17-19, 2015. The retreat drew from both the Blood Brotherhood and Dads in Action groups, to bring together a broad section of men involved in the hemophilia community. This retreat marked the first time the two groups have gathered, and we were glad to see some new men join the Blood Brotherhood as well.

During opening night the group learned many tips about emergency preparedness from Sim Wilkes, EMT, sponsored by the Hemophilia Federation of America (HFA). One interesting point was made about the value of taking the time to educate first responders in your area about hemophilia. One of the Blood Brothers shared his personal experience in working with first responders in his town, and verified that the education he provided was well received.

The remainder of the retreat was facilitated by Inalex Communications, represented by Haji Shearer and Rich Vogel. The overall theme was “Be Your Best Self.” The two led the group through various presentations,

exercises and discussions helping us focus on our values, our goals, and helping us generate greater trust with each other and honesty with ourselves. We worked in the group as a whole, in small groups, in pairs, and sometimes alone to reflect on who we are today, how we got here, and where we want to go in the future. Group members participated actively and enthusiastically through out the sessions.

After hours, we found plenty of time to hang out with each other, explore the beautiful camp area, play poker, have personal quiet time, enjoy fire roasted s’mores, and terrific steaks cooked to order by Blood Brother Jeff Neal (he brought his personal smoker grill to provide us with some fine eating).

We are eagerly hoping for a repeat in 2016, and want to welcome even more new folks next time around.



Education Around the State

With three educational dinners spread across the state, HNC staff was busy! In Raleigh participants learned about “Creative Conversations” in order to gain an understanding of how techniques like motivational interviewing help individuals living with bleeding disorders interact with caregivers and health care providers.

While in Charlotte, and then in Greenville, participants heard more about the connection between bleeding disorders and emotional well-being. Participants walked away from these dinners with new tools in coping and a much better understanding of the importance of mental wellness, whether you’re the patient or the caregiver.

HNC thanks Pfizer Hemophilia and their presenter, Daysi Fardales, MSN, ARNP-C, for partnering with us to make these educational events possible.

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

Workshop Presenters



Major Sponsors



Walk Kickoff Even at Lake Crabree County Park

By Ruth Mastrapa

The event started off with some very important hugs and catching up with friends we may not have seen since a previous event. I personally got involved in my first Hemophilia walk in 2008. My involvement with HNC began in 2001 after learning of my son's diagnosis in 2000 and wanting to meet other moms like myself, and I've been hooked ever since. The walks have always been an important time for me to get my family as well as myself more involved in volunteering and fundraising for the bleeding disorder community. I've found it's a great opportunity to give back!



At the kickoff, we sat on the park benches with the sun warming our spirits and listened attentively as previous walk facts were discussed; we knew to pay close attention. As we proceeded to play a trivia contest in which all of us won a fundraiser piggybank; we also discussed ways to help raise money through our teams or as an individual. There are various ways to ask our employers



to match our donations or possibly sponsor us; all we have to do is **ASK**. Have friends and family not only fundraise with us but also help spread awareness about Hemophilia of North Carolina.

There were games, stickers, crayons and corn-hole boards set up which the kids really enjoyed and some even customized their piggybanks. We enjoyed some delicious BBQ and for the finale there was even a magic & ventriloquist show!

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 **\$100,000.00!**

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Adult Retreat at the Beach

Everyone had a chance to get some sand between their toes at the 2015 HNC Adult Retreat! The retreat began with dinner and then a warm welcome from Charlene. Attendees introduced themselves to one another through a game called “two truths and a lie”, where you offer three statements and others must guess which one is a lie. Some were quite comical and others accidentally said three lies, which led to even more laughter! After dinner, attendees made s’mores by the campfire and had an opportunity to gaze at the beautiful full moon that evening.



The real fun began on Saturday with an insightful workshop entitled “Making a Great Impression”, led by Angela Kegler from the American Management Association and sponsored by Biogen. Angela used relatable situations to discuss how different approaches of communication can have a huge impact on the outcome. Attendees shared their own experiences, challenges they faced during a particular time in their life, and how the communication helped or hindered the situation.

After lunch, everyone was free to explore the area and head down to the beach for some R&R. The weather couldn’t have been more perfect for the dinner at the pavilion that overlooks the beach. Afterwards, attendees had the option of heading to the local miniature golf course to test their skills with some friendly competition!

Angela led another fantastic workshop on Sunday, “Win-Win Conversations”, which tied in nicely to Saturday’s discussion. Through answering a few questions, everyone was grouped according to their primary communication style, which ended up being exceptionally accurate to most. It was interesting to hear how each of these four styles can have their own unique approach when in discussion with others. Also, how one can use this in any conversation to benefit them and the other person so there’s opportunity for a win-win! Once we had these new tools in our kit, it was time to raffle off some great prizes and then head our separate ways until the next HNC event!



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

Workshop Presenter



Workshop Sponsor



Contributing Sponsors



Programas de la unión de Lation

La Unión Latina ha estado viajando por todo el estado este verano y otoño. Gracias a una subvención de Baxalta, HNC ha sido capaz de albergar dos eventos divertidos de la Unión Latina!.

El primer evento se llevó a cabo el 22 de agosto en el zoológico de Carolina del Norte en Asheboro. El clima estuvo perfecto para un día en el Zoo, con un sol hermoso y temperaturas no muy altas teniendo en cuenta que era Agosto! Después de un delicioso almuerzo, las familias participaron en el programa Hola “Mi Factor, Mi Cuerpo” presentado por Patricia Espinosa-Thomson, Educadora de Salud Bilingüe. Esto fue una gran sesión educativa que incluía información sobre hemofilia, tipos de hemofilia, cómo se hereda la hemofilia, diferentes tipos de hemorragias así como opciones de tratamiento disponibles tales como demanda/ profilaxis; y cómo seleccionar el tratamiento adecuado basado en las necesidades y situación de cada persona. Tras la presentación educativa, las familias disfrutaron de una visita al Zoológico.

El segundo evento se llevó a cabo el 19 de septiembre en Dave & Buster en Concord. El evento se llevó a cabo durante el mes de la Herencia Hispana honrando nuestro patrimonio y construyendo nuestro futuro. La tarde incluyó una celebración, almuerzo y el programa “Hola” sobre Acoso/ Intimidación presentado por Patricia Espinosa-Thomson y Yinell Núñez, educadoras de salud bilingüe.



Las personas fueron divididas en dos grupos, adultos y niños. Cada grupo se centró en cómo lidiar con la intimidación y el acoso dependiendo de la edad de cada grupo. Tras la sesión, las familias fueron a jugar el resto de la tarde en Dave & Buster.

Hay un evento más de Unión Latina planificado el 30 de octubre de 2015 en Raleigh.

La Unión Latina es un grupo HNC dedicado a atender a las necesidades de la comunidad Latina en Carolina del Norte que son afectadas por un desorden sanguíneo. Ser miembro de este grupo le proporcionará la oportunidad de aprender estrategias para hacer frente a trastornos sanguíneos como la hemofilia y la enfermedad de von Willebrand (vWD) y reunirse con otros que están enfrentando lo mismo.

Si usted está interesado en aprender más, o en ser voluntario para ayudar, por favor contáctenos a la oficina de HNC.



HNC Family Retreat

20-22 de Noviembre
Lake Junaluska, NC

Aparta la fecha para nuestro próximo Retiro Familiar Anual! Este año cruzaremos el estado con rumbo a las montañas de Carolina del Norte. A pesar que la temporada de otoño estará a punto de terminar aun veremos algunos hermosos colores sobres las hojas de otoño! Para este año, el Retiro Familiar se llevara a cabo del 20 al 22 de Noviembre en Lake Junaluska Conference & Retreat Center.



El retiro familiar siempre ha sido un evento popular, y se encarga de proveer la oportunidad para tener mas conocimientos sobre los trastornos hemorrágicos de tus hijos, además nos da la oportunidad socializar, relajarnos y fomentar la diversión en familia. El Retiro Familiar va dirigido a las familias que tienen hijos menores a 12 años y que padezcan algún trastorno hemorrágico. Las sesiones educativas y las actividades programadas están diseñadas para esta audiencia incluyendo a los padres e hijos.

Algunos de los programas planeados para este año incluyen sesiones de principios básicos sobre los

trastornos hemorrágicos, infusiones, estar alerta con los trastornos hemorrágicos, un programa enfocado a los hijos de padres que padecen algún trastorno hemorrágico y para darle un toque de diversión al retiro, se llevara a cabo un carnaval y una noche de juegos. Hemos estado escuchando sus solicitudes y como novedad para este año, proveeremos servicio de cuidado para niños de todas las edades incluyendo infantes.

Mantente alerta de nuestro sitio web y pagina de Facebook para mayor información y actualizaciones. Te esperamos!

HNC Celebración del día de fiesta



5 de Diciembre
Jamestown, NC

Marque su calendario, la celebración de día de fiesta del HNC se llevará a cabo el 5 de Diciembre en Jamestown (cerca Winston-Salem) en el castillo de McCulloch. Aunque no será en el castillo, estamos a sólo un corto paseo. Los bellos paisajes lo dejarán sonriendo. Somos afortunados de tener a Anita Smith, PNP, hablando ese día para nosotros. También tendremos comida, diversión y una visita de Santa con un regalo para todos los niños presentes.

Manténgase atento a la página de Internet HNC para más información e inscripciones. Estamos contando los días para celebrar las fiestas con Ud y los suyos!

Tu-Tu Madness at the Walk!



Get your tu-tus ready ladies!! We're looking forward to having a real strong representation from our women & girls at the upcoming Raleigh Walk. As in the past, we will have a booth at the walk dedicated exclusively to SOAR so that we can provide information to the community as well as sell our famous tu-tus to help raise funds to support the program.

We're always looking for a few good women to help volunteer! Opportunities specifically for the walks include making tu-tu's (how about a tu-tu making party at your house – they're easy to make and a lot of fun to do in a group), staffing the booth on walk day and of course, helping to raise funds by creating your own walk team. It's a great opportunity to get your friends and family involved too!

Treating Nosebleeds

By Sarah M. Aldridge, MS
Reprinted with permission from Hemaware



A glass-walled office offers no privacy when you're hunched over a trash can with a nosebleed. So says Michelle Cecil, past president of the United Students in Residence Halls at the University of Wisconsin-Oshkosh. For the 2015 communication studies graduate, bloody noses are the most public symptom of her type 1 von Willebrand disease (VWD). "There were times when I became very self-conscious, especially when people who didn't know me or understand what was going on were staring," Cecil says.

Nosebleeds can be more than a nuisance for women with bleeding disorders. Fortunately, there are ways to relieve symptoms and correct chronic problems.

The nose

Your nose is lined with a mucous membrane and contains blood vessels that warm the air you inhale. Most nosebleeds originate in a network of arteries near the front of your nose that is

Continued on page 13

Treating Nosebleeds *Continued*

easily injured. Trauma, allergies and high blood pressure also can cause nosebleeds. So can swimming in a chlorinated pool.

Stop it now

“The most effective way to stop a nosebleed is direct pressure on the septum,” says Jose Manaligod, MD, associate professor of otolaryngology (an ear, nose and throat [ENT] specialist) at the University of Iowa Hospitals and Clinics in Iowa City. Pinching the nostrils this way or using nose clamps encourages clot formation. But you have to do it for 10–30 minutes. “Applying a vasoconstrictor (which narrows the blood vessels), such as Afrin® spray, also works,” he says.

Try ice on the bridge of your nose, says Jim Munn, RN, MS, program coordinator at the University of Michigan Hemophilia and Coagulation Disorders Program in Ann Arbor. He is a co-author of the National Hemophilia Foundation’s (NHF’s) Nosebleeds brochure. Nosebudd™, a nasal icepack invented by a man with hemophilia, may also help. “It gives you both the ability to pinch, as well as have the icy part, which helps with vasoconstriction,” Munn says.

Some patients swear by salt pork. After rolling pieces of the raw meat into nostril-sized cylinders, you freeze them in a plastic bag. When ready to use, coat them with a lubricant and gently tuck them inside your nostrils for about 30 minutes.

Several prescription medications come in handy. Stimate (desmopressin acetate, or DDAVP) Nasal Spray® stimulates clotting in mucous membranes. It’s used in patients with VWD and mild hemophilia A. Amicar® (aminocaproic acid) is taken orally to prevent clot breakdown in mucous membranes. Over-the-counter options include NasalCEASE®, a nasal packing material, and NosebleedQR®, a powder. Several creams, foams and gels also aid in clot formation or prevent its breakdown.

After a nosebleed, take it easy. Avoid rigorous physical activity and stay away from hot foods. Gently blow your nose afterward, but don’t close one nostril. “That’s more pressure and it could start the process all over again,” Munn cautions.

En route to the ER

Call your hemophilia treatment center (HTC) to determine when to head to the emergency room (ER). “Anytime you’ve had a nosebleed that is not responding for more than an hour or if the blood is pulsating (fluctuating with your heartbeat),

you want to get to the ER as quickly as possible,” says Munn. There, the medical staff may put packing in your nose, which exerts pressure on the blood vessels to arrest bleeding.

Cauterization time

Kinzie Hemann of Reinbeck, Iowa, had recurrent nosebleeds from her type 3 VWD, the severest form. “She had a few that would not stop even with –factor,” says her dad, Josh Hemann. It was time to consult an ENT.

ENTs can seal ruptured blood vessels in the nose using chemical, electric or laser cauterization. “Our first line of defense is to use silver nitrate, a mild chemical, which we roll over the blood vessels,” says Manaligod. “For patients with bleeding disorders, we work hand in hand with the hematology department to create a treatment plan,” he says.

In 2013 when she was 3, Kinzie had her first cauterization. A year later, the nosebleeds returned with a vengeance—more than a dozen in a two-month period. Since a second cauterization in December 2014, the kindergartner has had only one minor nosebleed. “Her quality of life has been a lot better,” says her dad.

Know your nose

Moisture is key in preventing nosebleeds. Plug in a cool-mist humidifier and dab some petroleum jelly in your nostrils. “You can squirt Ocean® Saline Nasal Spray, which is just salt water, four to five times a day to make sure the mucous membranes are staying moist,” says Munn. Drinking water, sports drinks or other fluids also helps hydrate your body, he adds.

“Be self-aware of your body and what triggers bloody noses,” says Cecil. “Know your history so you know how to act on it.”

<http://www.hemaware.org/story/treating-nosebleeds>

Telling Your Story

Do you have something to say? We want to hear it! In the past we’ve highlighted women and girls from the SOAR Program within the newsletter so that the many members of this community can hear your voice and story! We know how many talented and inspirational women there are within HNC and we want to shine the spotlight on you!

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

An HNC Program for Girls and Women with Bleeding Disorders

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.*

Our Young Voices

Fall, 2015



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.

VWD Becomes a Hot Topic at the NHF Meeting

By Kai Stinson

The National Hemophilia Foundation (NHF) Convention in Dallas, Texas, in August was speaking quite literally with its theme, "Boots on the ground". A cute tag line for being in Texas, the convention brought new ideas and awareness to something that is a growing issue in the community as a collective. With almost half of the entire convention being focused on the von Willebrands Community, it is no surprise that people did not see this coming considering that following the 66th Annual Meeting in Washington DC; a summit meeting for VWD was held to address the lack of attention plus growing stigma and marginalization in the bleeding disorders community.



With multiple presentations, panel discussions, and discussion groups dedicated to VWD topics, it was hard to pick and choose just which ones to attend. I had the pleasure and opportunity of being on two of those panel discussions. The two panels were "Mr. VWD: Men and Boys" and "Everyone Counts: Camp and VWD."

Following the VWD Pre-Con on Thursday, the first panel I spoke on was "Everyone Counts: Camp and VWD" where we discussed issues concerning the lack of attention and involvement of people with VWD in Hemophilia based camps. Many ideas were brought to the table about how to include VWD kids in camp and making them feel a part of the group.



On Friday, the "Mr. VWD: Men and Boys" panel discussion was held. Attendees discussed both the current solutions and problems still in the community of VWD once again introducing new ideas and concerns to the community as a whole.

The 67th Annual Meeting was a huge step in the direction of advocating for VWD, and showed that the NHF organization cares about all bleeding disorders. With the upcoming NHF Annual Meeting and World Convention in Orlando next year, there should be a lot of anticipation to see what the Foundation has in store for us next.

NC Members Travel to Dallas



It was another great Annual Meeting by the National Hemophilia Foundation (NHF) in Dallas, TX, from August 13-15. HNC members in attendance had a chance to choose from a variety of sessions, including multiple tracks for: consumers; families; VWD; women; young adults; adult men; Spanish-speaking; partners, spouses and caregivers. In addition to attending the meeting, Charlene Cowell as well as Sharon and Warren Ingram had a chance to lead sessions while there. Some of the teens that attended the HNC/HSC Teen Retreat submitted masks they made during the retreat and NHF had them proudly displayed in the art exhibit! This was also an opportunity to meet and connect with people from around the country.

For the sixth straight year, HNC took home a trophy symbolizing the organization's support of the World Federation of Hemophilia (WFH). Next year, the NHF Annual Meeting and WFH World

Congress will be back-to-back, for the first time ever, in Orlando, FL. There will be opportunities for members to seek out travel grants so keep your eyes and ears open!



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www.CSLBehring-us.com COA13-08-0045 9/2013

Upcoming Events



NHF's Regional Inhibitor Conferences

October 9-11, 2015
Greenville, SC

The National Hemophilia Foundation (NHF) will be holding the Regional Inhibitor Education Conference in Greenville, SC, October 9-11, 2015. These meetings are designed to provide a small group setting where you can interact with healthcare professionals as well as other patients and their families. This conference is primarily for people who have never attended an Inhibitor Summit before and is limited to 25 families in order to allow each educational session to be highly interactive. As such, preference for enrollment and confirmation will be given to newly diagnosed families or those families that have never attended an Inhibitor Summit in the past.

Who Can Attend?

- Adults, teenagers and children with hemophilia A or B who currently have or once had inhibitors and their caregivers that **reside in the same household** are welcome to attend the meeting.

What's Included:

- Travel and lodging assistance for eligible patients and their caregiver(s)
- Conference locations that are accessible to wheelchairs and other mobility devices
- Educational sessions geared towards people with hemophilia with an inhibitor and their families
- An Interactive Education Camp for children (Ages 5-12)
- Childcare for infants-4 years old

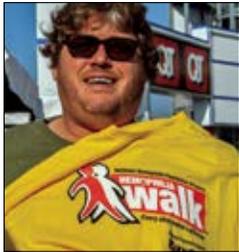
For more information, contact:

Research and Medical Information at National Hemophilia Foundation

Phone: 877.560.5833 Email: inhibitorsummits@hemophilia.org

Or visit the website at:

www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Regional-Inhibitor-Education-Conferences



Walking with a Purpose

October 17, 2015
Lake Crabtree County Park
Morrisville, NC

Where are your walking shoes? Dust them off and meet us at Lake Crabtree! October 17 is upon us, which means we're gearing up for the 8th Annual Raleigh Hemophilia

Walk and look forward to seeing everyone out there! This is our largest fundraiser and awareness-raising effort and we need your help to continue growing it as we have since 2008!



Did you know that Hemophilia of North Carolina was one of the first five Walk sites across the country? Now there are 40 and we're proud to host two right here in NC! For the October Walk we'll be at Lake Crabtree County Park in Morrisville representing the bleeding disorders community.

Ask your friends, family, and co-workers to show their support by joining in. There will be plenty to do! Sweet Tomatoes is coming out to provide breakfast and Starbucks will be there with some morning pick-me-up. Jecoreiography will get everyone pumped up as they dance along to the beats played by DJ Kevin McVerry. The Carolina Hurricanes and Stormy are coming out to entertain the kids with the Slap Shot Booth and Miller Motte will be providing some well-deserved massages. After the walk, Jimmy John's will be there in a jiffy with lunch for all! We'll also have treats for our four-legged friends – doggy bags donated by PetMania!

Of course raising funds is critical for the Walk's success, but we also have another goal. Hemophilia of North Carolina would like to see a record number of walkers this year, which translates into an increase of awareness for those not familiar with the community we serve. Please consider who you could invite to not just join in your fundraising efforts, but who could also join you at the Walk to introduce them to our special community! Think about people you know – friends, family, co-workers, sports teams, church, school – and send them an invite to join you. See you on October 17!

Upcoming Events Continued on page 17

Upcoming Events continued from page 16

HNC Community Yard Sale 2015

Saturday, October 24, 2015
 8am – 12noon
 260 Town Hall Drive, Morrisville, NC

Hemophilia of North Carolina is hosting a Yard Sale! HNC staff and volunteers will host a yard sale here at the office in Morrisville. If you plan to be in the area, we'd love to have you donate items or come by the HNC office to help us out!

Suggested items for donation include:

- Small furniture in good condition
- Video games
- Home décor
- Working appliances
- Books
- Shoes
- Dishware/cookware
- Clothes
- Music
- Jewelry, purses, accessories
- Electronics
- Artwork

Just give us a call toll-free at 800-990-5557 to coordinate with our staff when you can volunteer or drop off your items between now and Friday, October 23rd.

We're looking forward to a great turnout, and raising awareness in the larger community!

Upcoming Events Continued on page 18



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.

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#hemtour



thank you nurse Debbie #thankful



first catch



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Upcoming Events *continued from page 17*



Save One Life Comes to Durham

October 22, 2015
Morehead Manor, Durham, NC

Save One Life is a nonprofit international 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. Meet founder and president Laurie Kelley and executive director Martha Hopewell and learn more about how Save One Life supports hemophilia families

around the world! They'll be at Morehead Manor in Durham on October 22nd from 6:00-8:00pm. You are encouraged to bring a guest to introduce to Save One Life. Hearty hors d'oeuvres and drinks will be served. Registration is required; please call the HNC office for more information if you're interested in attending.

Blood Brotherhood Retreat

October 22-25, 2015
Corolla, NC

This year's Blood Brotherhood Retreat will be on the beautiful North Carolina Outer Banks from Thursday afternoon, October 22 to Sunday morning, October 25.

A few more details:

- The house is fully accessible and has an elevator.
- Linens will be provided, but towels and washcloths will not.
- There is a game room with billiards and an arcade game. Participants are encouraged to bring games that others may enjoy sharing.
- While meals are provided, snacks are not. Feel free to bring your favorite snacks and beverages.

Registration for this event is on a first come, first served basis, but priority will be given to HNC members who have actively participated in Blood Brotherhood events in the last 12 months.

Accommodations will be shared, and there is no fee for the event. Attendance will be limited to 18-20 men, so register early to reserve a space.



Accepted registrants will be contacted by phone to arrange carpooling as we approach the event. We will be asking some participants to carpool when possible to ease parking concerns.

Upcoming Events Continued on page 19



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Jecorei Lyons at (615) 542-2571

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Upcoming Events continued from page 18

Latin Union Event in Raleigh

October 30, 2015
Raleigh, NC

The next HNC Latin Union event is going to be October 30th in Raleigh. We'll be discussing the important topic of bullying and hope that you'll join us! Keep your eyes open for an email with details and also check the HNC website for registration.



HNC Family Retreat

November 20-22, 2015
Lake Junaluska, NC

Save the date for the Annual Family Retreat! This year, we are moving across the state to the North Carolina Mountains. Though at the tail end of the fall color season, there may still be some beautiful colored leaves on the trees! This year's retreat will be held from November 20-22 at Lake Junaluska Conference and Retreat Center.

Always a popular event, the Family Retreat provides the opportunity to learn about your child's bleeding disorder, time to socialize and relax, and time for your children to get to know each other! The Family Retreat is geared towards families who have a child under the age of 12 with a bleeding disorder. The educational sessions and activities are designed for this target audience including both parents and children.

Some of the programs that are planned this year include sessions on bleeding disorder basics, infusions, being active with a bleeding disorder, a program geared specifically towards the siblings of those with a bleeding disorder, a carnival, and game night. We have been listening to your requests, and new this year, we will be providing childcare for children of all ages including infants.

Keep your eyes on the HNC website and Facebook pages for updates and information on registering. Hope to see you there!



HNC Holiday Celebration

December 5, 2015
Jamestown, NC

Mark your calendars! The HNC Holiday Celebration will be held on December 5 in Jamestown (near Winston-Salem) at Castle McCulloch. Although we won't be in the castle, we're only a short walk away! The beautiful views will leave you smiling. We're fortunate to have Anita Smith, PNP, speaking at the Holiday Celebration. There will also be food, fun, and a visit from Santa with a gift for all the children in attendance.

Stay tuned to the HNC website for more details and registration information. Can't wait to spend the holidays with you and yours!





Blood Brotherhood Update

The Blood Brotherhood program continues to grow here in NC! If you are an adult male living with a bleeding disorder, consider joining Hemophilia Federation of America's Blood Brotherhood program. Many states participate locally and guys from across the nation join in online chats and discussion. This year, in NC, we enjoyed hosting events about emergency preparedness on July 17th in Parkton and financial planning in Concord on August 8th! The guys also enjoyed the Back to School Monster



Truck Bash at the Charlotte Motor Speedway!

We have hosted many events across the state this year and many more gatherings. We plan to close our year with our Beach Retreat event October 22-25th. Space for this event is limited and priority is given to active participants, check the HNC website for registration if available. Though our 2015 programming is coming to an end, there are plenty of opportunities to stay involved. Connect with guys on the forum and online chats through the HFA website, host or plan a gathering, or attend HNC events like the Walk and Holiday Celebration!

Stay tuned as we will release the dates for next year's programming and, as always, we want to thank Hemophilia Federation of America for making the Blood Brotherhood program here in NC possible.

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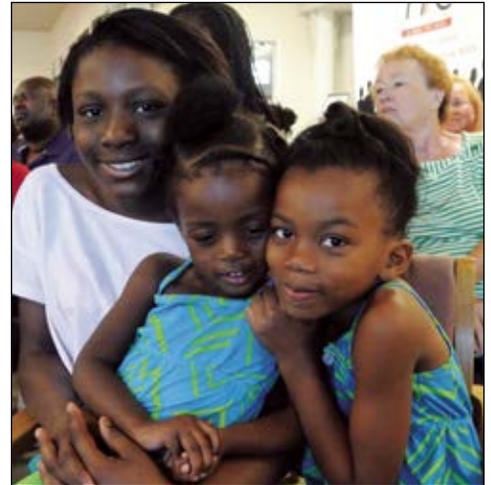
HOPE Update

- Help
- Opportunity
- Partnership
- Empowerment

Though HOPE has been quiet over the past few months, don't forget about the upcoming Family Retreat this fall. It will be held November 20-22. We will be at a new venue this year, Lake Junaluska Conference and Retreat Center in the North Carolina mountains. The Family Retreat is a wonderful program, held annually, that provides the opportunity to learn and meet other families.

HOPE is a program of HNC to support families with children from birth to twelve years old with a bleeding disorder. Open to any member of HNC, programs are geared specifically toward those families to educate and support them so that their children can lead a fulfilling life.

We are looking to expand our programming in 2016 to include more educational and social events. If you have any ideas for events, are interested in helping, or for more information about the HOPE Program, please contact Gillian Schultz, Program Manager, at gillian.schultz@hemophilia-nc.org or call the HNC office at (800) 990-5557.



Latin Union Program Updates

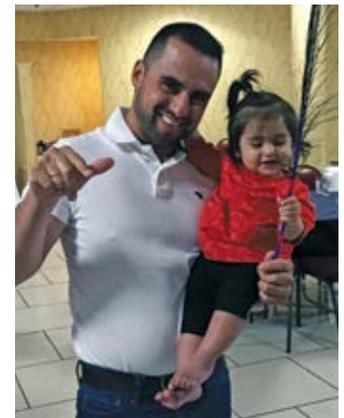
The Latin Union has been traveling across the state this summer and fall. Thanks to a grant from Baxalta, HNC has been able to host two fun Latin Union events!

The first event was held on August 22 at the NC Zoo in Asheboro. The weather was perfect for a day at the zoo, with beautiful sunshine and temperatures that weren't too hot considering it was August! Following a delicious lunch, families heard a Hello Talks! Program *My Factor, My Body*, presented by Patricia Espinosa-Thomson, bilingual healthcare educator. This was a great educational session that included information about hemophilia, including types of hemophilia, the genetics of how hemophilia is inherited, and different kinds of bleeds; treatment options including on demand and prophylaxis; and how treatment may be selected based on an individual's needs and situation. Following the educational presentation, families were treated to a visit to the zoo.

The second event was held on September 19 at Dave & Buster's in Concord. The event was held during Hispanic Heritage Month, *Honoring our Heritage, Building our Future*. The afternoon included a celebration, lunch, and the Hello Talks! Program about bullying presented by Patricia Espinosa-Thomson and Yinell Nunez, both bilingual healthcare educators. People were split into two groups, adults and children. Each group focused on how to deal with bullying at their stage of life. Following the session, families got to go play in Dave & Buster's for the rest of the afternoon.

There is one more Latin Union event planned this year on October 30 in Raleigh.

The Latin Union is an HNC group dedicated to serving the needs of the Latino and Spanish speaking community throughout North Carolina who are affected by a bleeding disorder. Being a member of this group will provide you with the opportunity to learn strategies to deal with bleeding disorders including hemophilia and von Willibrand disease (vWD), and meet with others who are dealing with the same thing.



If you are interested in learning more, or would be interested in volunteering to help, please contact us at the HNC Office.



Project CALLS

(Creating Alternatives to Limiting and Lacking Services)



Have you or a family member faced any limitations or restrictions from your insurance service that made it difficult to obtain necessary medications or

services? If so, Hemophilia Federation of America's (HFA) Project CALLS wants to hear your story!

This is an opportunity for you to share your story while helping the entire bleeding disorders community by speaking privately with a trained member of the HFA team about your insurance issues. Your participation in Project CALLS will allow the HFA to collect stories from the bleeding disorder community. With identifying trends, HFA will begin to build a case for changes to the insurance industry.

If you or a member of your family have been:

- **Denied** services or have received an exception,
- **Forced** by an insurance company to "fail" on a product before being allowed to use the product of your choice,
- **Mandated** to a pharmacy that is not meeting your needs, and/or
- **Forced** to go through a lengthy prior-/ pre-authorization process,

Project CALLS is for you!

To share your story through this very important initiative, contact Project CALLS at Hemophilia Federation of America directly about your insurance issue, please call (202) 836-2530 or email projectCALLS@hemophiliafed.org.

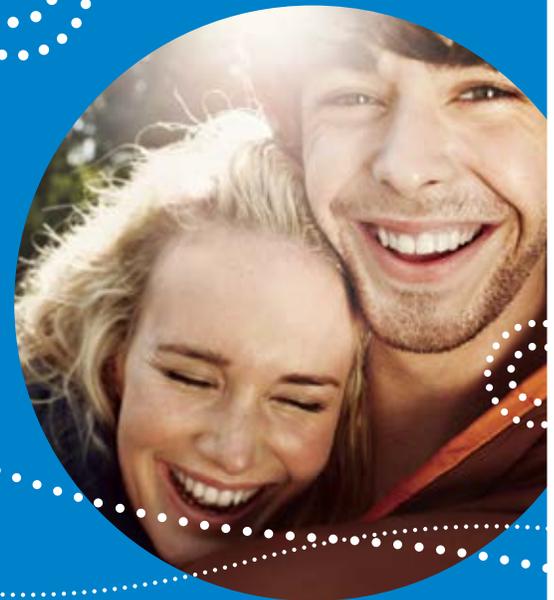
For more information, go to www.hemophiliafed.org/advocacy/project-calls/



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June 2014

NCABBD: Watchdog for Issues Dear to All of Us

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) convened its quarterly meeting on June 26, 2015, at the HNC Morrisville office.

The NCABBD brings together consumers and Hemophilia Treatment Center staff to review the landscape of North Carolina's bleeding disorder community. They look at everything, past, present, and future, that could affect our lives – 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.

The board met over a delicious catered lunch to discuss agenda items including reports from NCABBD members that included topics related to presentations at the HTC Region IV meeting, HNC staffing/events/initiatives, the HNC advocacy committee, HTC patient satisfaction surveys and contract pharmacies in NC. We appreciate the valuable conversation by those who participate in this advisory group.

The next meeting of the NCABBD will be October 9, 2015. 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.

Back to School with a Bleeding Disorder

By Gillian Schultz

I am very excited for this fall. The kids are back in school and I can't wait for the weather to turn a little cooler. Going back to school is an exciting, but also scary time, especially when your child has a bleeding disorder.

This year my son started at new daycare center. I needed to make sure they were prepared for what could happen with him. This year I decided not to bring my son's home healthcare or HTC nurse with me for the in-service. Instead, I was going to do it myself. Prepared with my PowerPoint Presentation I sat down in the room with my son's teacher and school director and started going through the presentation page by page. I didn't want to scare them, but at the same time I wanted to make sure they understood the seriousness of his bleeding disorder. It was so important to get across the point that my son is just like everyone else and should do the same things as everyone else. I don't want him limited on the playground or in the classroom. But I also want them to understand that he isn't like everyone else and something that might be nothing for another child could be serious for him because of his hemophilia. They were shocked to hear that I want and expect a phone call anytime he falls down or



bumps into another child. At times I had to stop myself because I saw the look of extreme fear on their faces and I didn't want them to be scared of taking care of him! I showed them a video of my son having an infusion and explained the process and that although it may be scary at times, hemophilia is just a part of our daily lives.

In the end, I know my son is safe and that they are going to look out for him! He has thrived so far this year in his new setting. This is the last year before he goes to elementary school. I have already started thinking about what I will need to do in

order to implement a 504 plan. I am sure that process will be a little more complicated than my small PowerPoint Presentation but well worth it to have the plan in place.

If you're wondering, I did not come up with the presentation on my own. NHF's Steps for Living has a variety of resources and HFA's Back to School Toolkit both helped be to put the presentation together. As I come across other situations where I will need to educate others about my son's hemophilia, I am sure I will be using those resources again along with the help of my HTC and HNC!

Raising Awareness with Nurses Across the State

Over the past year, HNC has exhibited at two nurses conferences with a third conference coming up in October. Our goal has been to raise awareness of bleeding disorders, provide educational materials and resources to the medical community, and to help the undiagnosed in getting proper treatment. Most recently, HNC staff and members attended the North Carolina Nurses Association's 108th Annual Convention. With over 300 nurses in attendance, we were able to hand out informational packets and discuss the signs and symptoms of bleeding disorders with nurses of varying practices. Our organization was welcomed and appreciated by all those who stopped by, and some even remembered us from the Nurse Practitioner Symposium earlier in the year. We were so glad to hear that we're making an impact!

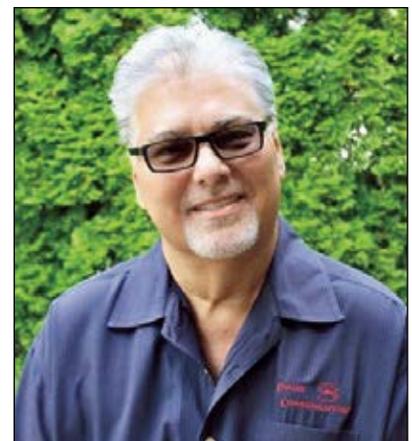
Next we'll be headed to the 32nd Annual School Nurse Conference in Greensboro, where we look forward to continuing our efforts. As we look to 2016, it is important that we continue reaching out to the medical community to

ensure that signs and symptoms of bleeding disorders are not overlooked. In a survey conducted by the CDC, they found that there was an average of 16 years between the onset of their bleeding symptoms and diagnosis of a bleeding disorder. We want to lessen that average and with your help we can do this! If you're interested in helping with this initiative please let us know!



Remembering Joe Caronna

It's with a heavy heart that we announce the passing of Joe Caronna, Founder and President of Inalex Communications Inc. Many of you will remember Joe and his infectious laugh from past HNC Adult Retreats, where Inalex Communications led our educational workshops. Joe has touched countless lives within and outside the bleeding disorders community and will be sorely missed by all who knew him.



Study Focuses on Cardiovascular Disease in Hemophilia Patients

As life expectancy in people with hemophilia (PWH) continues to rise closer to the national average, hemophilia healthcare providers have grown increasingly interested in the conditions most commonly linked to aging. One of the more pervasive of these is cardiovascular disease (CVD), and associated conditions such as ischemic heart disease (hardening of arteries) and atrial fibrillation (irregular heartbeat rate/rhythm). A multidisciplinary team of investigators conducted a scan and review of medical literature associated with CVD in PWH published between 1980-2013. Their findings, "Consensus Review of the Treatment of Cardiovascular Disease in People with Hemophilia A and B," were published in the March/April issue of the journal *Cardiology in Review*.

The lead author of the review was Victor Ferraris, MD, PhD, Tyler Gill Professor of Surgery, Division of Cardiovascular and Thoracic Surgery at the University of Kentucky in Lexington.

Ferraris and his coauthors acknowledged that data relevant to CVD in PWH is limited. That's because of the low numbers of hemophilia patients who have been documented with complications related to heart disease. The result is a lack of evidence-based guidelines from which to base treatment decisions.

"Accordingly, current recommendations for the medical and surgical management of common cardiovascular conditions in PWH derive from anecdotal experience and expert opinion. Most recommendations reflect guidelines and common practices for people without hemophilia," said Ferraris. "Ultimately, the rigorous, systematic investigation of management strategies for many cardiovascular conditions is unobtainable, given the relative rarity of hemophilia and even smaller numbers of PWH with any given cardiovascular condition."

However, Ferraris and colleagues did arrive at some conclusions. An examination of the literature suggested that low levels of factor VIII or IX did not necessarily offer hemophilia A or B patients extra protection against CVD conditions, including ischemic heart disease. In fact, the authors anticipate that older PWH will experience CVD rates comparable to the general population. Investigators added that recommendations relevant to the medical/surgical management of CVD in the aging PWH will be largely comparable to what is recommended for unaffected patients, as long as factor levels remain high enough to ensure adequate control of bleeds. They also acknowledged that the presence of an inhibitor to infused factor VIII or IX will complicate treatment and management in PWH/CVD considerably. The authors concluded that close collaboration between cardiology specialists and the comprehensive care team is crucial for quality clinical management.

"As the population of PWH ages, cardiovascular health care providers will encounter increasing numbers of PWH presenting with typical age related cardiovascular conditions, in addition to other acquired or congenital conditions spanning all ages," reported the authors. "To optimize resource utilization and clinical outcome and to minimize bleeding risk and complications, close consultation with a hematologist, ideally in association with a hemophilia treatment center, is essential."

www.hemophilia.org/Newsroom/Medical-News

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What's Happening on the Advocacy Front?

Hemophilia of NC (HNC) is always advocating for the bleeding disorders community and we wanted to take this opportunity to bring you up to speed on what has taken place so far this legislative session. Back in March, over 20 individuals joined us in Raleigh at the HNC Legislative Day; a great opportunity to have our voices heard and meet with our elected officials. Since then, our advocacy committee continues to meet the first Tuesday of every month and our advocates meet with legislators and key decision makers as needed. Advocacy is a great way to make an impact and ensure our needs are met when it comes to the care of our bleeding disorder community.

In April, the North Carolina Senate took a few minutes to recognize World Hemophilia Day and to acknowledge the role that HNC plays in serving and advocating for people with bleeding disorders in North Carolina.

In this legislative long session, state lawmakers were hard at work on the state's budget. Originally the effort to reform the state Medicaid program was integrated into the discussions over the budget. Now, lawmakers have removed the Medicaid reform debate from the budget process, and the Senate and the House are still negotiating between their competing proposals for Medicaid reform. Hemophilia of NC formally shared its position statement regarding the impact of capitation on those with hemophilia with key legislators, asking that hemophilia care remain in a fee for service model. Our most recent information shows there is a good chance that clotting factor will NOT be affected by Medicaid reform, although until a final bill is passed and signed nothing can be certain. HNC remains vigilant in monitoring the reform debate to ensure Medicaid beneficiaries with bleeding disorders have access to the specialty care and medicine they need.

Also this session the legislature created a Rare Disease Council, to advise the Governor, the Secretary, and the General Assembly on research, diagnosis, treatment, and education relating to rare diseases. HNC recognized this panel as an important opportunity for involvement by our community. The Secretary of the NC Department of Health and Human Services is currently reviewing the nominees for appointment to the panel. The appointments are not yet final and official, but we have good reason to believe the bleeding disorders community will be represented. This panel should be a good ally in our advocacy efforts in regards to rare diseases, which includes hemophilia and other bleeding disorders.

If you would like to hear more about our advocacy efforts or wish to advocate with us please join HNC's advocacy committee. Also, please check the HNC website for advocacy updates from Patient Services, Inc. (PSI) and to sign up for our advocacy list server to stay informed.



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for innovation,
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Baxalta

For more than 60 years, we've consistently pursued advancements in the treatment of bleeding conditions.

Now, as Baxter's BioScience becomes Baxalta Incorporated, this proven heritage—along with the advancements we're making today to cultivate tomorrow's developments—fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people—one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Victor
Patient, Baltimore, MD

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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.*

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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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