A chilly wind blew in their faces as they crossed the wide plaza that sprawls in front of the white-domed Capitol in Washington. The four volunteer advocates from the bleeding disorders community had a meeting scheduled in the Dirksen Senate Office Building on Constitution Avenue. Time was running short. It wouldn’t do to be late and they still had several blocks to go. Two of the four advocates were on foot. The other two rode electric scooters.

“Gentlemen,” said one of the two on foot, “we need to pick up the pace.”

The two advocates on scooters looked at each other, and without saying a word, they accelerated and sped away — leaving the two on foot to catch up as best they could.

In the space of one week in late February, two dedicated groups of volunteer advocates converged on Raleigh and then Washington in an effort to convince state and federal lawmakers to recognize the unique dilemma faced by persons with chronic illnesses and ultra-high medical costs. When the advocates told the elected officials (or their aides) what they pay in medical bills, the usual reaction was some version of “Wow! That much?” Winning sympathy is not the same thing as changing public policy, but it’s a start. And these advocates did more than win sympathy. Please read on.

RALEIGH — Hemophilia of North Carolina made arrangements for more than a dozen volunteer advocates from the bleeding disorders community to assemble at the North Carolina General Assembly on February 20 and educate state lawmakers about the realities of paying for...
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.

VISON STATEMENT
Hemophilia of North Carolina’s vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Tom Bennett
(919) 319-0014

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.

We maintain a membership mailing list. However, we never release any personal information without your permission. You may occasionally receive information that is mailed from our office. Your response to these mailings will be of your own choosing and if you would like to “opt out” of all third party mailings, please contact us to remove your name from these mailings.

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
Pedictric 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

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

Presbyterian Blume Pediatric
Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

American Pain Foundation (APF)
1-888-615-PAIN (7246)
American Society of Pediatric Hematology/Oncology
847-275-4716
www.aspho.org

Bleeding Disorders Legal Hotline
1-800-520-6154

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

ClinicalTrials.gov
A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial’s purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)
1-800-488-2688
www.cott1.org

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

HIV/HCV Newsletter
Hemophilia Association of the Capital Area
www.hacacares.org

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

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

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

World Federation of Hemophilia
514-875-7944
www.wfh.org
Dear Friends,

Not all good things come to an end. With dedicated support and a bit of luck, a good thing can go on and on and, as long as it fills a need, it should continue. Hemophilia of North Carolina will celebrate its 40th anniversary at the Annual Meeting coming up on May 4th. The theme of the meeting will be: “Hemophilia of North Carolina — 40 Years of Friendship & Opportunity.” It’s well to remember that HNC’s vision is “for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.” I submit that HNC is one of those good things that can and will go on for as long as it is needed. And brothers and sisters, HNC is needed.

Persons with bleeding disorders and their families face all the same life challenges as everyone else — plus the hardships of coping with a chronic illness. One of the toughest of those hardships is dealing with the cost of care. Annual care costs of $300,000, $500,000 or more than a million are not unusual. Next to the very few among us who are wealthy, the luckiest are those who have good health insurance, but even they face a formidable array of premiums, deductibles and co-payments.

There’s Medicaid and Social Security disability coverage, but not everyone is eligible. Our North Carolina General Assembly recently enacted a bill that deliberately bans Medicaid expansion and leaves 500,000 North Carolinians without coverage. Gov. Pat McCrory has signed it into law. Meanwhile, enrollment in Inclusive Care (the state High Risk Pool) has been frozen. The open insurance enrollment offered by the Affordable Care Act won’t be available until January 1, 2014. On top of all that, cuts to the federal budget — whether they be through the now-infamous “Sequestration” process or other sources — threaten the strength of the nation’s healthcare safety net, including Hemophilia Treatment Centers.

It’s no wonder that recent advocacy efforts such as HNC’s Advocacy Day and the National Hemophilia Foundation’s Washington Days have drawn strong and even record participation. [See this edition of the CONCENTRATE for stories on these events.] Our community is struggling, but thanks to HNC, NHF, and HFA, our community has a voice and the means to work for more enlightened public policies.

Yes, it’s true that we’re playing against long odds, but we are far from helpless.

Aside from assistance with the cost of care, the community’s next biggest need may be reliable information. Our friends in the healthcare industry put out a lot of information. Much of it is excellent and industry deserves full and fair credit for all that it does, but it is vital for the bleeding disorders community to have a source of information that has no bias and faces no perception of bias — except a bias in the consumer’s favor. HNC is first, foremost and always for the members, and it provides a level playing field where all reputable sources of information can contend on equal terms. Our industry friends support HNC precisely because they know that we put our members first. In serving them, we protect their identities and help assure that any marketing done at our events stays within bounds. HNC’s loyalty to its members — and their loyalty to HNC — are the rock on which this organization stands.

We live in challenging times. If HNC did not exist, the bleeding disorders community would be obliged to re-invent it at great trouble and expense. Your next opportunity to support the community and the continuing work of HNC is the 2013 Annual Meeting scheduled for Saturday, May 4, at the Greensboro Marriott Downtown. Plan to attend and help celebrate “40 Years of Friendship & Opportunity.”

Warmest regards,
Tom Bennett

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**From the Executive Director**

**Hemophilia of North Carolina**

**2013 Annual Meeting**

*Saturday, May 4, 2013*

Greensboro Marriott Downtown
304 N. Greene Street
Greensboro, NC
The realization was like a thunderbolt. My son Jacob, seven years old at the time, had just been diagnosed with von Willebrand Disease. His hematologist said, “He got it from either his mother or his father. Who should I test?” At that moment, everything made sense. I’d been living with the symptoms of a bleeding disorder my whole life, but I wasn’t diagnosed with von Willebrand Disease until I was in my 30s.

When I shared the news with close friends, some reacted with a shrug: “You’ve had it your whole life — what’s the big deal?” I experienced treatable symptoms for too long, and I even made a premature decision about fertility because of it. Knowing the cause of symptoms that plagued me for years was a big deal to me.

Sue Fletcher, SOAR’s founder, introduced me to SOAR in 2011. It was comforting to know that I wasn’t the only woman dealing with this. I enjoyed the fellowship with a group of courageous women who shared the common bond of living with a bleeding disorder. But I soon realized that SOAR is about so much more than just fellowship, and I’m happy to have the opportunity to serve as the Volunteer Program Coordinator.

SOAR is a group of supportive women within HNC who are committed to enhancing the quality of life of girls and women with bleeding disorders through Support, Outreach, Advocacy and Resources. These caring and inspiring women are reaching out and educating our community, advocating for your sons and daughters, and providing resources to school nurses to better prepare them for taking care of our children. We are committed to supporting women with bleeding disorders and to reducing the length of time that women suffer before being diagnosed. From the onset of symptoms, it takes an average of 16 years for a woman with a bleeding disorder to be diagnosed.

We welcome all girls and woman who have bleeding disorders or care about someone who has a bleeding disorder to become a member of SOAR and participate in our upcoming events. We will be hosting several fun events this summer that you won’t want to miss! Whether you are looking to socialize or become involved with our efforts we have a spot for you.

You can sign up now to be part of SOAR:

1. Join HNC online at http://www.hemophilia-nc.org/Membership/application.html and check SOAR under HNC programs; or
2. If you’re already an HNC member, request a SOAR information packet at http://www.hemophilia-nc.org/SOAR/info-req.html; or
3. Call HNC at 800-990-5557 (toll free). Register now so we can include you in our summertime fun!
Toothbrushes for Christmas

Those attending HNC’s 2012 Holiday Celebration were asked to bring toothbrushes to the December 1 event so that the international health service charity, Save One Life, could distribute them to needy people overseas. Attendees responded by bringing hundreds of brushes and plenty of toothpaste. Here’s the response from Laurie Kelly, founder of Save One Life.

Dear Tom,

I want to thank you and the families and staff of Hemophilia of North Carolina from the bottom of my heart for your wonderful gift of toothbrushes for children with hemophilia who live in impoverished countries. What an outpouring of a very important necessity for these children! While it seems like a minor thing, dental care, especially for those with hemophilia, and especially those in developing countries, is vital to good health. And the children treat them like prized possessions.

I just packed them up yesterday to bring to Nigeria. Sadly, I won’t be accompanying our executive director Martha Hopewell on this trip, as I am tied up with administrative work in the office. But Martha has promised photos, which we will share with you for your excellent newsletter. We reserved a few for a future trip, perhaps Haiti.

Please share my thanks with all who donated. I continue to be impressed and humbled by our wonderful hemophilia community!

Warm regards, Laurie Kelly

The Gilbert family of Malawi was among those who received toothbrushes and toothpaste donated by members attending Hemophilia of North Carolina’s 2012 Holiday Celebration.
ASHEVILLE – Under the watchful eye of a Glass Center worker, a Blood Brother drew a long steel pole from the fiery white mouth of the gas kiln and extracted a glob of molten glass eight times hotter than boiling water.

Carefully he carried this glowing item to a double-armed workbench and began to roll the pole back and forth to form the glass into the shape he wanted. He made a snip with some heavy-duty scissors and twisted the raw ends of the now doughy glass with what looked like a pair of calipers. This done, the Blood Brother took it back to the kiln and heated it again. Later, when the glass had solidified, he had

Continued on page 7
Blood Brotherhood: Cool as Glass

Continued

a sea-blue paperweight inside of which a brilliant orange star would always swirl. A hot item turned into something cool!

The HFA Blood Brotherhood affiliated with Hemophilia of North Carolina sponsored a trip to the Asheville Glass Center on Saturday, Feb. 16. Matt Igelman, BB Site Manager, and eleven other Blood Brothers had a chance to work molten glass into beads, buttons and paperweights. They were playing with fire — safely — and the end products were beautiful and durable art objects that some will keep for their entire lives.

At the conclusion of the glassblowing session, the Blood Brothers adjourned to The Arcade in downtown Asheville, where they ate a hearty Mexican dinner and received advocacy training from Leonard Poe, who serves as Advocacy Chairperson and Vice President for Hemophilia of North Carolina. Leonard spoke on current legislative issues including Medicaid expansion and the state high-risk insurance pool.

MORRISVILLE — The Blood Brotherhood Game Night held at the HNC office on Saturday, March 9, blended the fun of video games and corn hole toss on the patio with serious instruction on pain control techniques and physical therapy counseling. Jeanne van Gemert of Duke Integrative Medicine spoke on pain control through meditation and helped the Blood Brothers practice some of those techniques. Meanwhile, Jennifer Newman, a physical therapist from the Hemophilia Treatment Center at UNC, offered individual counseling sessions for all.

Dinner was ordered from the Bonefish Grill in Cary and included the diner’s choice of steak or fish — with sides. The baked Wolf Fish tasted like a slice of heaven.

Funding for Blood Brotherhood activities comes from a U.S. Centers for Disease Control grant via the Hemophilia Federation of America.

Baxter’s vision is a life without bleeds

At Baxter, we will not stop until our vision of a life without bleeds is a reality for all.

Over the years, Baxter has been the leader in providing support and resources for the community.

Today, we are continuing to improve treatment for bleeding disorders. We have seven ongoing clinical trials, including those targeting hemophilia A, hemophilia B, inhibitors, and von Willebrand Disease.

For people with bleeding disorders, the future has never been brighter. As we increase the time between infusions, someday regular infusions, as we know them, may be distant memories.

To us, continuing to make a meaningful difference one person at a time is our passion and what’s behind our unwavering commitment.

Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.
Meet HNC’s new Walk Manager – Laura Meyers

Hemophilia of North Carolina is thrilled to introduce our 2013 Walk Manager, Laura Meyers. Laura comes to us after four years with The Women’s Center (now Compass Center for Women and Families) in Chapel Hill. Laura served first as Volunteer & Development Coordinator before being promoted to Director of Career & Legal Programs.

As Volunteer & Development Coordinator she worked closely with the Executive and Development Directors, assisting with events both large and small, and she was also the lead staff person for Orange County’s Women’s History Month events in 2011 and 2012. As point person for all volunteers interested in serving The Women’s Center, Laura was the face of the organization, assisting potential volunteers in finding the right opportunity and navigating the training process. Laura also managed the website and monthly newsletters.

Laura resigned from her full time position after the birth of her son, Leo, in May 2012. Her desire to have more time at home with her new family and her passion for non-profit work guided her to the HNC Walk Manager position. Laura grew up in Yancey County, and she now lives in Durham with her son, husband Ben, and two dogs Miles and Adele.

HNC Annual Meeting:
Celebrating Our 40th Anniversary

Hemophilia of North Carolina’s 2013 Annual Meeting will celebrate “40 Years of Friendship and Opportunity.” The meeting will be held Saturday, May 4, at the Marriott Downtown in Greensboro. It’s going to be a meaty meeting that offers lots of useful information. The featured speakers will include: Dr. Alice Ma, speaking on “New Developments in Hemophilia Care;” Ms. Johanna Gray, speaking on “The Affordable Care Act at Three—The Rubber Hits the Road;” Ms. Kristy Lee, “What You Need to Know about Genotyping,” and Daysi Fardales, MSN, ARNP-C, speaking on “Living a Healthier Lifestyle Through Physical Fitness and Nutrition.” In addition we’ll have a new member orientation, breakouts for teens, men and SOAR members or potential members, and a picnic dinner!

Donate your care, truck, RV, motorcycle, boat or just about any other vehicle to Hemophilia of North Carolina. It’s easy! Look for the link at the top of the HNC web site at www.hemophilia-nc.org.
2013 Friends of HNC

We gratefully acknowledge the following individuals who generously donated to Hemophilia of North Carolina during the past quarter of 2013, and we extend a special thanks to our supporters who contributed several times during this quarter.

Donors

David and Sally Frost
Sieglinde Uffelman
in honor of Dalton & Heather Dawes
Carol Parks
in honor of Rusty Parks
Kevin Brown
Mara Purcell
Mallory O’Connor
Sue and W. Allen Heafner
Don and Cindy Manning
in honor of Team Wonderfully Made
Dr. and Mrs. Gilbert White
in honor of Team UNC Tarheelers
Daryl Steinbraker
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thanking all who supported his fundraiser
Lori Conger
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Donations supporting the Caldwell-Moody’s Flapjack Fundraiser

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James and Robin Clark
Adiana Kipp
Mellissa Huntley-Kee
Delbert and Amy Elwood
Scottie and Marcy Edgison
Matt Igelman
Tat’yana Shchetinina

Donations in memory of Sara Nix

Bruce and Delores Fry
Bruce and Mable Howell
The Nix and Payne Family
¡Saludamos de nuevo a nuestra querida comunidad latina! Este año promete estar lleno de acción para toda la comunidad de desordenes sanguíneos. Una vez mas la Asociación de Hemofilia de Carolina del Norte ofrece una amplia variedad de eventos recreativos y educativos con el fin de ayudar a nuestras familias a salir adelante ante las dificultades y desafíos que un episodio de sangrado traer para todos dentro de la familia. Cada programa brinda consejos de utilidad, recomendaciones y recursos para los participantes. Dentro de estos programas, encontraran aquellos que se ofrecen en español y diseñados específicamente para todos aquellos que han venido desde otros países a buscar el tratamiento adecuado para sus seres queridos. Durante este año HNC tiene planeado varias celebraciones: El mes de los niños, la llegada del verano, y uno de las mayores festividades culturales de México: El día de los muertos. En la Asociación sabemos que las familias se encuentran dispersas a lo largo y ancho del Estado de Carolina del Norte, y que las distancias para acudir a veces son muy largas, por lo que te invitamos a ponerte en contacto con nosotros para ayudarte a que vengas a nuestro eventos, o mejor aun, iremos hasta tu ciudad a ofrecer nuestros programas educativos.

Sera un placer tener como participante en cada uno de nuestros programas en español, pero recuerda también que te esperamos en los eventos principales de la Asociación: Reunión Anual de HNC, La Caminata de Hemofilia (Hemophilia Walk), y La Celebración de Navidad. Te prometemos un caluroso recibimiento y todo nuestro apoyo para ti y toda tu familia.

¡Esperamos verte pronto!

Hello there dear Latino community! This year promises to be action-packed for the entire bleeding disorders community. Once again Hemophilia of North Carolina is offering a variety of educational and recreational events to help our families cope with the difficulties and challenges that a bleeding episode can bring to the whole family. Each program is full of useful tips, recommendations and resources for the participants. There will be programs presented in Spanish and specially designed for those who have come from Latino countries to find the right treatment for their loved ones. This year HNC will celebrate children, the arrival of the summer and one of the major cultural-holidays celebrated in Mexico: The Day of the Dead. We know that all families are spread across the State of North Carolina, so please if you have not yet had the opportunity to join our program because of the driving distances, contact us and we will either help you to come, or even better, we will go to your city!

It would be a pleasure to have you participate in each one of our Spanish programs, but also remember that HNC would be honored by having you come to its main celebrations: the HNC Annual Meeting, the HNC Walk and its Holiday Celebration. We promise you that at each of these events you and your family will find nothing but support and warmness.

Looking forward to seeing all of you there!!
Para nuevos lectores y miembros

**Misión:** Hemofilia de Carolina del Norte es una organización no lucrativa, dedicada a mejorar la calidad de vida de personas afectadas por algún desorden sanguíneo, brindándoles apoyo en educación, promoción de estudios de investigación y promoviendo programas y servicios para esta comunidad.

**Nuestra Visión:** Que todas las personas afectadas por algún desorden sanguíneo alcancen el desarrollo total de sus capacidades, sin barreras o limitaciones, hasta que se encuentre una cura.

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**¿Cómo ser un buen defensor de tus derechos al vivir con algún desorden sanguíneo?**

Muchas personas con algún desorden sanguíneo encuentran saludable - emocional y, aunque difícil de creer, físicamente - el tomar parte activa dentro de organizaciones dedicadas a defender sus derechos y el de los otros que viven con la misma condición de salud. Sin importar tu edad, o si tienes un hijo recién diagnosticado, o incluso, si eres amigo de alguna persona con algún tipo de desorden sanguíneo, cualquier momento es el correcto para comenzar a aprender a defender tus derechos y el de los demás.

En ocasiones, al estar ante la decisión de convertirte en un activista por una causa –en este caso: La defensa de los derechos de las personas que viven con algún desorden sanguíneo –, la primera pregunta que viene a tu mente es quizás “¿Tengo la energía, habilidades o la personalidad para ser un buen defensor de mis derechos?” Pues bien, ten en mente que las actividades para defender una causa - ¡Tu Causa! - son infinitas y tomas muchos matices. Puedes dedicarles tiempo completo, o algunas horas a la semana, de cualquier forma, tu dedicación y tiempo ayudarán a conseguir los objetivos de la organización a la cual estés apoyando.

**Todos tenemos alguna habilidad o conocimiento que puede ayudar**

Una vez tomada la decisión de participar activamente, has una lista de los objetivos, a largo y corto plazo, de tu organización. En el caso de la comunidad de personas que vivimos con algún desorden sanguíneo, los objetivos pueden muchos: Acceso para todos a un tratamiento adecuado, programas de difusión acerca de las características de los desordenes sanguíneos, cursos de capacitación para prevenir y tratar sangrados, participación movimientos para exigir a las autoridades que le den la importancia y apoyo suficiente a nuestra comunidad, o cualquier otra actividad que sigan el objetivo de mejorar la calidad de vida de las personas con desordenes sanguíneos y sus familias.

**Recuerda:** La clave para ser un buen defensor y promotor de quienes vivimos con algún desorden sanguíneo es……

**Informarte primero, para educar después.**

Sabemos que en ocasiones, aunque desees participar dentro de las actividades de la Asociación de Hemofilia de Carolina del Norte (HNC), te es imposible el hacerlo formalmente debido a tu trabajo u otro tipo de obligaciones, pero no te desanimes, puedes ayudar a cumplir sus objetivos a través de acciones personales que promuevan los derechos de la comunidad de desordenes sanguíneos.

Si tienes interés en participar activamente, acércate a la Unión Latina de HNC y entérate de que forma nos puedes apoyar. ¡Con la pequeña participación de todos podemos alcanzar grandes objetivos!

**Consejo Rápido**

La importancia del “Lote”, de tus medicamentos.  
*(Lot, en inglés):*  

Mantén un registro del número de Lote de todos tus medicamentos, en especial de los que se inyectan.

Este número puede ayudarte a identificar medicamentos que las compañías farmacéuticas han detectado como inseguros para su uso. Además, en caso de efectos secundarios o reacciones adversas, la información de este número le ayuda a estas compañías a realizar más investigación y desarrollar mejores productos.

Utiliza una libreta únicamente para apuntar los números de “Lote”

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!Únete a nuestro grupo!
Hemophilia Federation of America Symposium, April 25-27

The Hemophilia Federation of America (HFA) holds an annual community-centered educational event, called Symposium. This year’s Symposium will be held in Dallas, Texas on April 25-27, 2013. This family-friendly conference draws close to 600 patients, families, exhibitors, and speakers from around the country. Symposium offers community members the opportunity to become strong self-advocates and to connect on a personal level with other patients living with a bleeding disorder.

HFA is a non-profit 501(c)3 organization incorporated in 1994 to address the evolving needs of the bleeding disorders community. HFA is an active consumer advocate for safe, affordable, and obtainable blood products and health coverage, as well as a better quality of life for all persons with bleeding disorders.

Hemophilia of North Carolina supports HFA, and among other collaborative activities, HNC hosts an active Blood Brotherhood group (see related story, this edition). Our site coordinator is Matt Igelman, and the group holds educational and fellowship meetings six times per year. Recently, the group held a glass-blowing session in Asheville that was combined with advocacy training.
You may be eligible for a FREE one-time 1-month supply up to 20,000 IU of factor* from Pfizer Hemophilia

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

A "Car, Truck and Motorcycle Show” organized by Helen “Daisy” Blaquiere was held in Spring Lake on March 30 and raised almost $1,000 for Hemophilia of North Carolina. Everyone had fun, and the display of vehicular style and beauty was awesome. Thanks and congratulations!
When I was in grade school, I remember dreading physical education. Although my sports talent was as developed as a circus clown’s talent for subtlety, I enjoyed shooting hoops and throwing a ball. So why the dislike of PE? Because for me, being the crippled kid who was made of glass, PE meant sitting on the bleachers, watching the “normal” kids play dodge ball, floor hockey, and freeze tag.

Luckily, my parents were ahead of their time in their approach to hemophilia, encouraging me to ride my bike, play ball, and be normal. But my teachers (especially in PE) back in the 1980s were fearful. Many of them simply chose to sideline me safely on the benches while they and the normal kids spent an hour having fun. For me, this was dispiriting and humiliating. When recess came and we were all released from the confines of our classrooms, nobody wanted to pick the hemo-whatchacallit kid to be on their team, and why would they? If I couldn’t even throw an underinflated dodge ball in PE, then how good could I possibly be on the basketball court?

It was a no-win situation and the primary reason I eventually found my way into the school band. It was ironic: all through my school years, our sports teams were Bad-News-Bears terrible while my band won trophies, I dated hot clarinet players, and I eventually got to play my saxophone in China. So it worked out. Mostly. I do still daydream about my unrealized superstardom playing professional dodge ball, but in the end, I wound up where I’m supposed to be.

Still, it hurt that my PE teachers viewed me as a fragile kid they couldn’t risk putting into the thick of things because I might break. Granted, this was the 1980s and I, a clumsy and severe hemophiliac, was on cryoprecipitate, so bleeds were drawn-out affairs. I might fall and bleed a little, but I would gladly have traded an ankle bleed for the chance to participate and be accepted by my peers. But the adults in charge couldn’t help looking at me through hemo-colored glasses.

Skip to today. We “hemos” are experiencing a renaissance in living with our condition. Our factor is now safe and effective. We have a vast support structure of hemophilia treatment centers (HTCs), national and local chapters, and foundations. Some of our blood sisters and brothers do continue to struggle with inhibitors, but progress is even being made there. Life isn’t perfect, but it’s good. I often encounter frazzled parents who lament that their child is a “bleeder,” express regret and guilt about passing on the condition, and even proclaim their refusal to have more children. I am conflicted when I meet these parents.

Continued on page 15
On the one hand, they do have a difficult job. Parenting isn’t easy even when things are nearly perfect, so throw in a bleeding disorder and you increase the difficulty and stress exponentially. But on the other hand, I can’t help thinking, it’s just hemophilia! Though that may be a shocking statement, I challenge everyone to step back a moment and really reflect on it.

Yes, hemophilia is a bleeding disorder. Yes, it’s expensive and time-consuming. But what isn’t it? It isn’t a death sentence. It isn’t a barrier. It isn’t cancer or MS or sickle cell anemia. It isn’t a lot of things that are much worse. For hemos today, the world is as accessible and open as for any clotter, and we hemos are now everywhere, doing all the things they do. We climb mountains. We ride bicycles coast-to-coast. We play golf, soccer, basketball, and yes, even football.

For hemophiliacs in the 21st century, there is truly no logical reason to accept being considered anything other than normal, even by those who love us most: our parents. I often hear a standard set of statements: “I feel guilty that he is in pain,” or “I regret that he has to suffer,” or “I feel bad when he cries.” I understand all of those. Yes, we hemos hurt. We sometimes suffer. We even cry. But who doesn’t? What kid doesn’t fall down and cry sometimes? Who doesn’t suffer from something? Unless Kal-El has landed and hopped from his Kryptonian pod into some cornfield, I doubt that there is a single kid anywhere who doesn’t suffer in some way, hemo and clotter alike.

Ultimately, I hope that parents facing guilt or regret can find the strength, courage, peace — or the driving force they need — to take that step back and examine whether their feelings are realistic and beneficial for themselves, and most important, for their little bleeder. Think of this exercise as “prophy for the soul.” Kids are far more observant and aware than most adults realize, and regardless of how deeply you’ve buried your guilty feelings, your child will pick up on them. Your hidden guilt could inadvertently tell your child, “You aren’t really normal.” After all, would you feel guilty for your child’s brown hair? Or green eyes? Then why hemophilia?

Hemo parents have one of two paths to walk: they can eventually choose to wipe away fear and doubt and to fully accept their child’s hemophilia and normality; or they can wear the hemo-colored glasses my PE teachers wore, acting out of genuine concern and love, but seeing the disorder first and the kid second. We hemos thrive when walking hand-in-hand down the first path — not so much the second. Which path do you choose?

Jeff Johnson lives in Washington with his wife Stephanie.

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health care. At that point, the General Assembly, which is dominated by Republican majorities in both chambers, had not yet passed SB 4 — No NC Exchange/No Medicaid Expansion — though it was well on its way to enactment.

As the title states, the bill aims to prevent North Carolina from participating in the pending Health Benefit Exchanges proposed by the Affordable Care Act and to prevent expansion of Medicaid benefits to persons making up to 138 per cent of the Federal Poverty Level. SB 4 is a flat rejection of what our state’s political conservatives term “Obamacare.” In practical terms, it means that: (01) the state is turning away billions of healthcare dollars, (02) 500,000 North Carolinians will not be covered by an expanded Medicaid program and (03) the Health Benefit Exchange where North Carolinians can buy reduced-rate coverage will not be operated by the state or a state-federal partnership, but by the federal government.

Currently, Medicaid and the State Children’s Health Insurance Program (SCHIP) cover people with bleeding disorders—but only if they are very young, very old or disabled. A related problem is that Inclusive Health (the North Carolina High Risk Pool) has recently frozen new enrollments, and now limits prescription costs for current members to only $100,000 per year. With these kinds of challenges blowing in the political wind, the bleeding disorders community needs to speak up.

After a continental breakfast and a thorough briefing presented by Advocacy Chair and HNC Vice President Leonard Poe, the HNC volunteer advocates armed themselves with fact sheets and fanned out to visit more than thirty legislators and legislative assistants as well as Lt. Governor Dan Forest, who presides over the N.C. Senate. Lt. Gov. Forest received an information packet and promised to present it to NC Health & Human Services Secretary Aldona Wos. Later in the afternoon, Leonard Poe and two other advocates were introduced to the full Senate via a ritual called “Courtesy of the Gallery.”

No one seriously expected the Advocacy Day effort to stop the passage of SB 4, (Gov. Pat McCrory ultimately signed it into law during a private ceremony held on March 6.) but the volunteer advocates raised awareness of hemophilia and other bleeding disorders, made contacts that could prove useful in the future, and opened the prospect of “carving out” some sort of special provisions to help people with chronic, high-cost illnesses.

Almost twenty participants took the time to appear in Raleigh and made the effort to speak out on behalf the bleeding disorders community. On that day the community had an especially strong voice and used it well.

Special thanks should be expressed to Bayer HealthCare and to CSL Behring for their generous grants in support of Advocacy Day.

WASHINGTON – More than 300 volunteer advocates gathered here on February 27-March 1 for the National Hemophilia Foundation’s Washington Days. They were given two main objectives: (01) to persuade members of Congress to support continued federal funding for hemophilia treatment (via the Health Resources and Services Administration [HRSA] Maternal and Child Health Bureau and the CDC Division of Blood Disorders), and (02) to urge members of Congress to back legislation to prevent insurance companies from setting up “specialty tiers” that would jack up the patient cost of certain prescription medications—particularly biologics such as clotting factor. Cuts to HRSA and the CDC could jeopardize staffing at Hemophilia Treatment Centers (HTCs), cut back on monitoring the safety of the blood supply, hamper efforts to improve treatment and prevention strategies, and make access to specialized care more difficult. Specialty tiers present the threat of making it even harder to find affordable, quality healthcare.

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harder for members of the community to pay for their medication, and if the creation of specialty tiers can be stopped at the federal (nationwide) level, all the better.

The event began on Wednesday with an orientation session for first-time attendees. Experienced Washington lobbyists explained the protocols and traditions of lobbying elected officials on “The Hill,” site of the U.S. Capitol. On Thursday morning busses took everyone to the Capitol Visitor Center, a subterranean labyrinth that lies beneath the east plaza of the Capitol. With all the bustle of tourists, lobbyists, Congressional staffers and security police, the place resembled a nest of fire ants.

In the underground Visitor Center Auditorium all the advocates received a briefing from U.S. Rep. David B. McKinley (R-West Virginia), the chief sponsor of HR 460, the Patient Access to Treatment Act. His bill, which is co-sponsored by Rep. Lois Capps (D-California), would require insurance companies to treat biologic medications (such as factor) no different than other prescription drugs and impose no higher co-pays than they already do for Tier III drugs. Unlike the flat-rate co-pays for other drugs, “specialty tiers” oblige patients to make payments of 25 percent, 33 percent or more on the total cost of their medications. When one considers that patients who need factor routinely face annual costs of $300,000, $500,000 or—sometimes—more than $1 million, the dire implications of specialty tier payments are painfully clear.

After their briefing, the volunteer advocates formed into teams and began visiting senators, representatives or their aides at the six congressional office buildings that flank the north and south sides of the Capitol. This involves much walking outdoors on the grandly proportioned boulevards of Washington or obtaining permission to thread the maze of underground tunnels that connect the buildings. Security is tight and dead serious. To use the tunnels or enter any of the Congressional office buildings, one must undergo an airport-style security screening, and woe to anyone who has a small pocketknife or an aerosol bottle of cologne. Visitors’ hands and clothing are checked for traces...
of explosives. In the course of the morning visits, one North Carolina team passed through six different security checks.

The office buildings were all large and impressive, but their interiors varied dramatically. Some were richly adorned with brass fixtures and polished marble. The older ones had a sort of GI look reminiscent of old war movies — exposed pipes and room numbers stenciled on doors with black paint. Most of the offices were small and crammed with staff members. The conference rooms ranged from grand to strikingly plain. An aide to one representative conversed with his guests in a storage room complete with stacked boxes and cage partitions.

State teams visited scores of senators, representatives or — often — their aides. The aides proved to be earnest young adults who listened carefully, took notes and promised to convey the visitors' concerns to Representative X or Senator Y. Some of the aides were well versed in healthcare issues; others appeared to be less knowledgeable, but all were unfailingly cordial.

The North Carolina delegation, which included ten members, visited 6 to 10 lawmakers or their aides. As a result of the day's work, NHF officials announced that volunteer advocates had recruited at least five additional House co-sponsors for HR 460. It remains to be seen what effect the budget “sequester” will have on hemophilia funding, but after Washington Days, more members of Congress should know what is at stake for some of their most vulnerable constituents.

These days the U.S. Congress is often described as a dysfunctional place, a governing body that is gridlocked and corrupted by the influence of wealthy special interests. However true that may be, NHF Washington Days proved that one of the fundamental features of democracy is alive and well: the right of the people to petition their elected leaders.

The four volunteer advocates reunited at the security screening station on the C St. NE side of the Dirksen Senate Office Building. Despite another laborious security check and a cramped elevator ride up to the fifth floor, they got to their appointment on time.
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**MEMBERSHIP INFORMATION**

The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

**For new members,** Please complete the application form at right.

**For existing members,** we are currently updating our database and would like to make sure we have the most current contact information for you. Please take a moment to fill in the application and check “currently active member – information update”.

Please mail completed application to:
Hemophilia of North Carolina
260 Town Hall Dr., Suite A
Morrisville, NC 27560

OR send an email to info@hemophilia-nc.org with all the information OR fill out a membership form at www.hemophilia-nc.org under “Membership”.

If you would like to make a donation, please make checks payable to Hemophilia of North Carolina. Your donation may be tax deductible to the extent allowed by law. We are pleased to send you a receipt for your donation.

**Membership Application**

- [ ] Currently active member - information update

  - Name:_____________________________________________________________
  - Address: ___________________________________________________________
  - City: ______________________________________________________________
  - State: ____________________ Zip:  ____________________________________
  - Home Phone: _______________________________________________________
  - Cell Phone: _________________________________________________________
  - Email: _____________________________________________________________
  - Check One
    - [ ] I am a person with a bleeding disorder.
      - Type __________ (VIII, IX, VWD, etc.)
      - Inhibitor? _______Yes _______No
    - [ ] I am a family member of a person with a bleeding disorder.
      - Relationship __________________________
      - Age (if child): __________
      - Type __________ (VIII, IX, VWD, etc.)
      - Inhibitor? _______Yes _______No
    - [ ] I am a medical professional.
    - [ ] I work in an industry providing products or services to persons with bleeding disorders. Company name: __________________________
    - [ ] None of the above, but I am interested in bleeding disorders and HNC activities.
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 and a member of the Better Business Bureau.

Hemophilia of North Carolina

2013 Annual Meeting

“40 Years of Friendship and Opportunity”

May 4, 2013
Greensboro Marriott Downtown
304 N. Greene Street
Greensboro, NC