

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2012

## Tom Bennett Named as HNC's New Executive Director

Hemophilia of North Carolina is pleased to announce the hiring of Tom Bennett as its new Executive Director. Tom has strong ties to North Carolina and a distinguished record as a non-profit executive serving several statewide organizations.

Though he was born and reared in Knoxville, Tennessee, Tom has deep North Carolina roots that run from the mountains to the sea. His father's family is from Yancey County, and he still has relatives who live in and around Burnsville. He has lived in the Piedmont section of North Carolina for almost thirty years. Going farther east, his last duty station in the U.S. Coast Guard Reserve was Base Fort Macon at Atlantic Beach, from which he participated in search-and-rescue missions near Cape Lookout and elsewhere along the coast.

He holds a B.A. degree from Maryville College and a master's degree from the University of Tennessee. Though he trained as a journalist and began his professional life as a newspaper, television and wire service reporter, he has almost thirty years' experience as a non-profit executive and more than 20 years as a lobbyist at the N.C. General Assembly. He has served as Executive Director of the N.C. Dental Society, the N.C. Association of Rehabilitation Facilities, and the N.C. Association of County Directors of Social Services. Most recently he served as Executive Director of the North Carolina Victim Assistance Network (NCVAN), an organization that helps crime victims statewide. For six years he led the North Carolina Child Fatality Task Force, a legislative

*Continued on page 5*



## Plans for NC Hemophilia Walk 2012 Well Underway!

Planning for the NC Hemophilia Walk 2012 is already well underway! The Walk will be held on October 20th, 2012 at Lake Crabtree County Park in Morrisville. Thus far, we have raised over \$22,000 in local support with a goal of \$80,000. We are also anticipating having more than 1,000 walkers attend the event this year!

In order to get the Walk underway, HNC has selected a Walk Chair for 2012. Because of their hard work and determination last year, Crystal Hoernlein and her family will be the 2012 Walk Chairs. Last year, the Hoernlein family hosted a

*Continued on page 5*



### Inside

HNC Resource Center  
Chapter News & Information  
Latin Supplement  
On the Health Front  
On the National & Legislative Front

### Save The Date

HNC Advocacy Committee  
Conference Call, 7 pm  
First Tuesday of the Month

2012 NC Hemophilia Walk  
Kickoff Event  
North Carolina Zoo  
Asheboro, NC  
August 11, 2012

SOAR Retreat  
Blowing Rock, NC  
August 17-19, 2012

HNC Family Retreat  
Pine Knoll Shores, NC  
September 1-3, 2012

NC Advisory Board  
For Bleeding Disorders  
Q3 Meeting  
September 7, 2012

Latin Union Retreat  
September 14-16, 2012

Blood Brotherhood &  
Partners Program  
September 27, 2012

NC Hemophilia Walk 2012  
Lake Crabtree County Park  
Morrisville, NC  
October 20, 2012

NHF Annual Meeting  
Orlando, FL  
November 8-10, 2012

HNC Holiday Celebration  
December 1, 2012

NC Advisory Board  
For Bleeding Disorders  
Q4 Meeting  
December 7, 2012



*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

**Executive Director, Tom Bennett**  
(919) 319-0014

**National Hemophilia Foundation Office**

(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  
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

**Wake Forest University Baptist Medical Center**

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Medical Center Boulevard  
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Fax: (336) 716-3010

**Additional Medical Resources**

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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  
http://htc.medicine.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)  
Hemophilia Chronic Pain Support Group  
http://painaid.painfoundation.org

**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.

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www.uneedpsi.org

**World Federation of Hemophilia**

514-875-7944  
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, until a cure is found.



# From the Executive Director

Dear Friends,

When you start a new job, such as serving as Executive Director of Hemophilia of North Carolina, the list of things you know seems like an anthill compared to the mountain of things you don't know. I'll admit that is true for me, but I have an advantage because I've already had the pleasure of meeting some of you at the Adult Retreat in Winston-Salem, at the Annual Meeting in Durham, and elsewhere. Those opportunities for me to hear and observe members of this unique community have proved invaluable. Here's what I've learned, and I'd be glad for you to contact me and tell me if my first impressions are correct.

01. The people affected by hemophilia, VWD and other bleeding disorders are a diverse group. You come from every walk of life, every point on our state map, every racial and ethnic group and every spot on the social and economic spectrum. No stereotype could capture who you are.
02. You love your friends and families, and whether you have a bleeding disorder or it afflicts a relative or friend, you are concerned about what the future may hold.
03. Unless you happen to be ultra rich (and most of us aren't) paying for medical care is a big, big issue. Home care, medications and other forms of treatment are breathtakingly expensive, and you spend more time than most people worrying about insurance coverage (or the lack of it), Medicare, Medicaid, SCHIP, Social Security disability payments and related matters.
04. You may be angry. Some of you, especially those who are newly-diagnosed or have a newly-diagnosed loved one, may be asking very understandable questions such as: "Why me?" or "Why do our public health policies make it so difficult to get help?" and "Why are so many people – the general public, elected officials and even some members of the medical community – so woefully ignorant of bleeding disorder and the special needs of those who have them?" And more than a few of you are engaged in a lifelong struggle with other blood borne illnesses – such as HIV – that entered your life years ago when our nation's health care apparatus failed to guard the blood supply from pathogens. You have every right to ask, "Why didn't the health authorities see this coming and take preventive measures?"
05. Most of you – though not all – think of yourselves as belonging

to a community, the community of those struggling with bleeding disorders. Though I'm a newbie, I am already willing to argue that this sense of belonging is your most important asset and your best hope for building a better future through shared information and united action. That's where Hemophilia of North Carolina comes in. Every community needs a community center, and many of you see HNC in exactly that way.

06. It is clear that my predecessor, Sue Cowell, was widely liked – even loved – by many of you in this community, and I am fortunate to succeed such a capable and popular Executive Director.
07. HNC is blessed with a highly capable and very dedicated staff and Board of Directors. I can tell when people are committed to a cause, and these people are committed. Like your sense of community, their dedication – their energy – is very impressive and more precious than gold.

I could list other insights, but these are the ones I consider most important. What do you think? Am I getting it right? I'd be grateful if you would contact me and share your thoughts about my assumptions and about anything else that affects this wonderful organization's capacity to improve your life. I can be reached at [tom.bennett@hemophilia-nc.org](mailto:tom.bennett@hemophilia-nc.org) or call me at (800) 990-5557.

I am delighted to be here, and I look forward to getting to know more of you as the weeks and months go by. These are tough times, but if we stick together and work together, we can build a better life for everyone in the bleeding disorders community.

Tom Bennett  
Executive Director

## Thank you Sue Cowell

for your able leadership as our Executive Director from 2007-2012, which brought our organization to new heights improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research, and supportive programs and services.

— *The Members and Board of Directors of Hemophilia of North Carolina and all people with bleeding disorders whose lives you have touched.*





## In Memory of Terry Lamb

Terry Lamb, a beloved member of HNC, passed away on May 29th, 2012. As a member of HNC for many years, Terry was an avid supporter of our chapter and was an inspiration to many. He never let hemophilia or any other health issue prevent him from enjoying life to the fullest. While Terry may be best remembered for his role as resident auctioneer at Casino Night, he was also a member of the HNC Aging Research Team and volunteered to speak with parents of newly diagnosed boys with hemophilia. His smile and good humor enlivened any HNC event. Terry's dedication to the bleeding disorder community was evident not only by his commitment to HNC but also by his involvement with the Maryland, South Carolina and Virginia chapters as well. Terry worked tirelessly for Hemophilia Federation of America (HFA) as a FitFactor program speaker and was elected to HFA's Board of Directors in March 2012. His passion to exercise and stay healthy motivated countless others to focus on self-empowerment and health. Terry touched the lives of many and he will be greatly missed.

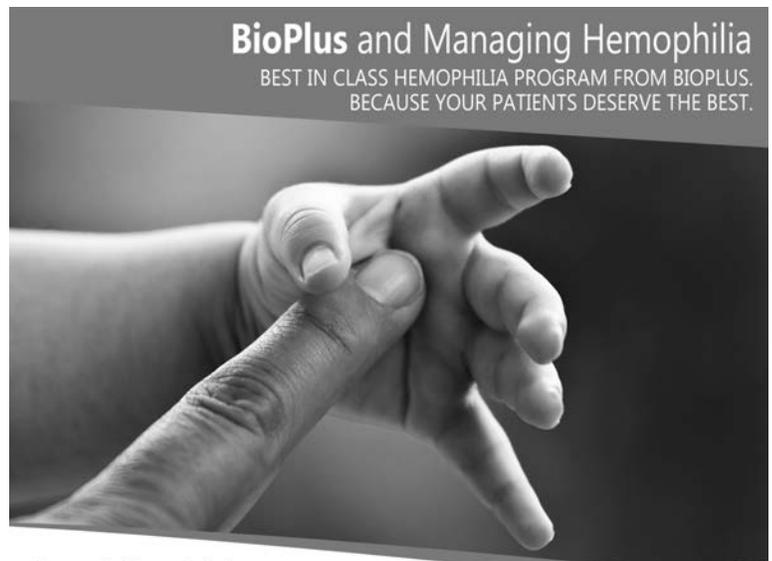
## Welcome to Our New Board of Directors!

A new Board of Directors was voted into office at the HNC Annual Meeting on May 19th 2012. Welcome to Michael Hoernlein, our newest member. Returning and re-elected board members are Steve Peretti (President), Leonard Poe (Vice President & Advocacy Chair), Kathy Register (Treasurer), W. Scott Andrews, Tiffany Holland, Steven Humes, Warren Ingram, Maria Schnaith-Ivan, Amy Shair Miller, Ann Skinner and Sally S. Wright. Many thanks to our board members for their long-time devotion to the bleeding disorders community!

## HNC Member Morgan Cook Wins TEA Award



One of HNC's own, Morgan Cook, is Hemophilia Federation of America's 2012 Teach, Empower, Advocate (TEA) award recipient! The award is presented annually at the HFA symposium to recognize an individual's outstanding support of women with bleeding disorders. Morgan, who has VWD, was nominated for her invaluable participation during the recent SOAR regional dinners. She traveled across North Carolina to share her experiences related to intimacy, couple communication, and family planning with other women. Although she is a full-time teacher, Morgan did not hesitate to travel wherever the events were being held, even if it meant an extremely long day. Her openness and honesty allowed attendees to freely share their own concerns. Morgan is much loved by SOAR members and we are very proud of her!



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## Tom Bennett Named as HNC's New Executive Director *continued*

commission that studies all causes of child deaths and advocates for laws to protect children's lives. His legislative successes include the state's Graduated Drivers' License law, the smoke detector penalty law, and work on behalf of the State Children's Health Insurance Program (S-CHIP).

He and his wife, Carol, have lived in Cary for twenty-seven years. Carol works as a Project Leader at the corporate headquarters of Golden Corral. Tom and Carol are the parents of Zack, an Eagle Scout who now attends AB-Technical Community College in Asheville. Tom's pastimes include: reading, woodworking, writing mystery novels, hiking and greenway bicycling.

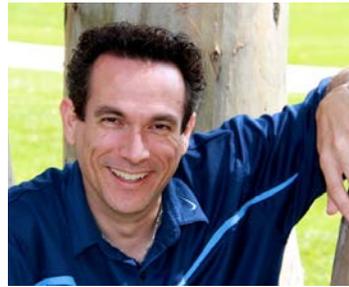
Tom officially started work on June 4, but many HNC members had the opportunity to meet him and Carol at the HNC Annual Meeting in May and the subsequent Durham Bulls game. He also attended the Adult Retreat in April and has already gotten a big head start as he learns more about bleeding disorders and HNC.

*Welcome aboard, Tom!*

*HNC gratefully acknowledges the hard work of president Steve Peretti, who was joined by HNC stalwarts George McCoy and Charles Register on the executive*

*director search committee. Board members Amy Shair Miller and Sally Wright joined the committee for the second round interviews, and three finalists were presented to the full board. We were very fortunate to have interviewed several highly qualified and experienced applicants, and especially pleased to have Tom at the top of the list.*

## New HFA President is One of Our Own!



Congratulations to our own Matthew Compton! He was recently elected as new board president of the Hemophilia Federation of America's (HFA). He was elected after serving the organization as Vice President since 2009.

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## Plans for NC Hemophilia Walk 2012 Well Underway! *continued*



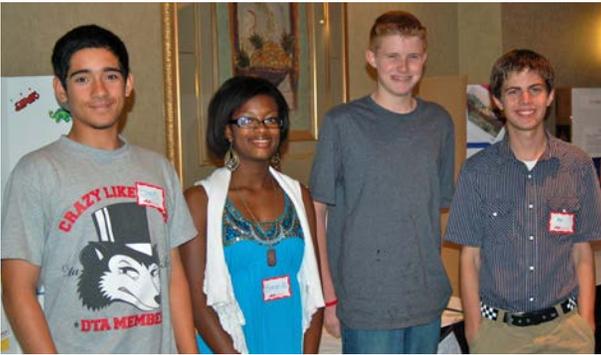
very successful mystery dinner and gave all the proceeds to their walk team, Team Jacob. Their original idea and very hard work helped them raise \$1,551.72. I want to thank Team Jacob and all

of the other hardworking teams from last year for setting such a great example. I am looking forward to all of the fundraising ideas our teams will come up with in 2012.

We are currently seeking sponsorships, so contact us if you have a company or organization that might be interested in sponsoring the Walk. Our thanks to local corporate sponsors who have already committed their support: Novo Nordisk, Walgreens Hemophilia Services, Grifols and HPC International. Sponsorship Packets are available by calling 800-990-5557 or emailing Nicole Bailey, 2012 Walk Event Manager, at [nicole.bailey@hemophilia-nc.org](mailto:nicole.bailey@hemophilia-nc.org).

Information about the Walk is available on HNC's website [www.hemophilia-nc.org](http://www.hemophilia-nc.org) or you can register directly for the Walk at [www.hemophilia.org/walk](http://www.hemophilia.org/walk). We are looking forward to another great Walk this year and hope to see each of you there with your walking shoes on!

*Nicole Bailey, 2012 Walk Event Manager*



## Volunteer Dinner Honors Good Work, Raises Global Awareness

On the Friday evening before HNC's Annual Meeting, 83 people gathered in Durham for a delicious meal and a moving presentation by hemophilia luminary Laurie Kelley. Laurie compared U.S. access to hemophilia care with access abroad. Her message, filled with hope and optimism, nevertheless highlights vast inconsistencies in hemophilia care across the globe.

The annual invitation-only event celebrates the remarkable people who have volunteered for HNC in the past year. Four teens from our community presented a sidebar to Laurie's program, with graphics and bleeding disorder statistics from Japan (Shawn Mastrapa), Mexico (Emma Ingram), Thailand (Jesse Cornaire), and France (Kai Stinson). *(l-r in accompanying photo).*



## Brenda Nielsen Honored

Brenda Nielsen, Hemophilia Nurse at the Treatment Center in Chapel Hill and Adjunct Assistant Professor in the School of Nursing, was honored in the presence of 83 volunteers at HNC's 2012 Volunteer and Special Guests Dinner. Board member and colleague Sally Wright presented the award to Brenda, which reads: "For Two Decades of Caring & Commitment to the Hemophilia & Bleeding Disorders Community." Sally echoed the sentiment of generations of colleagues and patients when describing Brenda as the backbone and the heart and soul of the Hemophilia Treatment Center. "Her calm, always ready, down-to-earth, get-it-done style," along with her computer-like powers of recall about the specific needs of each of her many patients, make her a gift to all of us.

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*Are You a Savvy Consumer?*

# Annual Meeting Takes on Timely Issue



With the fate of the Affordable Care Act teetering in the Supreme Court as of this writing, the theme of HNC’s 39th Annual Meeting, “Are You a Savvy Consumer,” was a welcome subject to a large contingent of the North Carolina bleeding disorders community. Some 204 adults, children, and representatives

of industry sponsors attended the Saturday, May 19 event at Durham’s Sheraton Imperial Hotel and Convention Center. Event organizer and former HNC President Richard Atwood was our Master of Ceremonies, and with his tall, striking appearance and his duck call, he was able to move the proceedings so that our educational presentations did not fall behind a very packed schedule. Early planning was conceived by Sue Cowell before her departure after five years as our Executive Director. Event details were hammered out by Charlene Cowell, Maria Schnaith-Ivan,

and Tiffany Holland with help from numerous volunteers. They are all to be congratulated for a superb event.

The morning began at 8AM with breakfast and an orientation for first-time attendees, ably facilitated by our very own Sue Fletcher, PhD, and board member Sally Wright, MSW, LCSW. Next was our Keynote Program – an informative, hands-on symposium presented by Pulse on the Road—a traveling version of the Insurance Pulse feature of LA Kelley Communications’ PEN Magazine. Among those on the dais were Laurie Kelley and Michelle Rice, insurance expert from NHF. Even the most seasoned consumers in the room learned from the excellent presentation that featured total immersion into the arena of Preferred Provider Networks and Health Management Organizations. The session encouraged planning ahead to reap the most benefit annually from one’s insurance carrier’s offerings. High risk pools, COBRAs, donut holes, Medicare, Medicaid, annual and lifetime caps did not go unmentioned.

HNC’s annual business meeting was next. President Steve Peretti wielded the gavel as the membership took care of required business, then elected a 2012-2014 Board of Directors. Steve then introduced our new Executive Director, Tom Bennett, who subsequently began work on June 4, and whose hiring is featured elsewhere in this issue of The Concentrate. The last order of business was to thank Sue Cowell for her five extraordinary years building our chapter into a national presence.

Afternoon breakout sessions continued our theme. Dan Fox, Advocate with Disability Rights North Carolina, presented Understanding Your Rights. Don Molter, Career Counselor, Indiana Hemophilia & Thrombosis Center, presented Special Needs Education (504 Plans) & Individualized Education Programs (IEPs). Helen Shapiro, RN, Chapel Hill Hemophilia Center, and Dr. Sue Fletcher, principal investigator for HNC’s Aging Research Study, presented Self-Empowerment: How to Get the Most out of your Medical Visits. Leonard Poe, HNC’s Vice President for Advocacy, presented Advocating for your Needs. Robin Kellerman, RN, BSN, MSS and a Nurse Consultant, presented Research, Clinical Trials, & Studies, and Michelle Rice presented Standard of Care for Service.

The day’s schedule was paralleled by a Children’s Track and a Teen Track, in which our kids had their own workshops, outings, and fun with food - facilitated by Tiffany Holland and Charlene Cowell with help from volunteers. Durham Bulls tickets and dinner vouchers were distributed following the door prize drawing and closing of the meeting.

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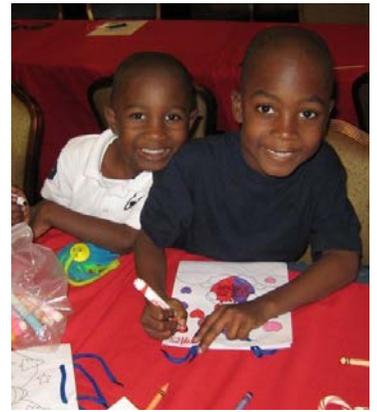
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## HOPE for New Members of the HNC Community

Are you or a family member newly diagnosed or new to the area? Have you heard of HOPE?

HOPE (Help, Opportunities, Partnership, and Empowerment) is a program designed specifically for new members of North Carolina's bleeding disorder community. When first getting a diagnosis or when moving to a new location, we understand that your family has specific needs. HOPE is here to help! We have peer-lead support groups as well as other programs that you and your family can take part in. Please contact Nicole Bailey at HNC's office or email [nicole.bailey@hemophilia-nc.org](mailto:nicole.bailey@hemophilia-nc.org) for more information. We look forward to hearing from you soon!



## Ageing Research Study – Only a Few Spots Left!

We've had a great response to our Ageing Research Study but still have room for a few more participants! Please pass along the following information.

HNC is seeking research participants for a study entitled Health-Related Quality of Life Among Older Men with Hemophilia. The two-year study, initiated by Hemophilia of North Carolina, is designed to obtain new knowledge about hemophilia and aging that may provide important information to enhance care. All men aged 50 and over with a diagnosis of hemophilia are eligible to participate. Spouses, partners and care providers are also being recruited. All information will be kept confidential and no personal information will be released to third parties outside of Hemophilia of North Carolina. All participants will be compensated for their time.

For more information, please contact Sue Fletcher, PhD at [sue.fletcher@hemophilia-nc.org](mailto:sue.fletcher@hemophilia-nc.org).

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Our  
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## Save the Date!!!

August 17th-19th

The Annual SOAR retreat will take place at the beautiful Chetola Resort in Blowing Rock, NC. Join us for a weekend in the beautiful North Carolina mountains! We will share our experiences and participate in fun & supportive activities!



This retreat is for:

- Girls and women with a bleeding disorder (age 13 and up)
- Women with a daughter who has a bleeding disorder
- Women diagnosed as a symptomatic carrier of hemophilia

If interested please email Nicole at [nicole.bailey@hemophilia-nc.org](mailto:nicole.bailey@hemophilia-nc.org) to get more information or to register. This event is graciously sponsored by CSL Behring.

## 2012 Friends of HNC

*We would like to acknowledge the following individuals who generously donated to HNC during this quarter of 2012.*

*We extend a sincere thank you to our supporters, many of whom contributed several times during this period.*

### Donors

Bruce & Pat Andrews • Carolyn Bailey  
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# Unión Latina de Hemofilia



Hemophilia Latin Union

## Tom Bennet asume el cargo de Director Ejecutivo de HNC

(Translated from HNC website)

Tom, quien es originario de Knoxville, Tennessee, tiene un fuerte arraigo con el estado de Carolina del Norte. La familia de su padre es de Yance County, y aun tiene familiares que viven en los alrededores de Burnsville, NC. Durante los últimos 30 años, Tom ha vivido en el área de Piedmont Carolina del Norte. Su mas reciente responsabilidad dentro de la Reserva de la Guardia Costera de E.U., la realizó al en la costa este del estado, en la Base de Fort Macon .



Tom cuenta con los títulos de licenciatura y maestría obtenidos en la Universidad de Tennessee. Aunque sus estudios los realizó en periodismo, y comenzó como reportero para periódicos y televisión, actualmente cuenta con casi trece años de experiencia como miembro ejecutivo dentro del sector de las organizaciones sin fines de lucro, y mas de veinte años como activista de la Asamblea General de Carolina del Norte. Ha ocupado la posición de Director Ejecutivo para las siguientes asociaciones: Sociedad Dental de Carolina del Norte; Asociación de Espacios de Rehabilitación de Carolina del Norte; y para la Asociación de Directores de Condado de los Servicios Sociales. Su mas reciente posición como Director Ejecutivo fue dentro del Sistema de Asistencia para Víctimas de Carolina del Norte (NCVAN, por sus siglas en inglés), organización que brinda apoyo a las víctimas de crímenes a lo largo del estado. Dentro de su currículum también encontramos que estuvo al mando por seis años del Grupo para Evitar la mortalidad Infantil de Carolina del Norte, el cual fue parte de una comisión legislativa para investigar las causas de los fallecimientos infantiles y fomentar leyes para proteger la vida de los niños. Algunos de sus logros legislativos incluyen The State's Graduated Driver's License Law, The Smoke Detector Penalty, y sus actividades legislativas para beneficio del Programa de Seguro de Salud para Menores de Edad.

Su esposa Carol, con la que lleva casado veintisiete años, trabaja como Líder de Proyecto en las oficinas corporativas de Golden Corral. Carol y Tom son padres de Zack, un talentoso scout, quien ahora se encuentra estudiando en El AB– Technical Community College en Asheville. Los pasatiempos de Tom incluyen: la lectura, carpintería, escritor de novelas de misterio, excursionismo y bicicleta de montaña.

Tom comenzó como Director Ejecutivo a partir del 4 de Junio de este año, sin embargo algunos de los miembros de HNC ya habían tenido el gusto de conocerlo al lado de su esposa, dentro de las actividades de la Reunión Anual 2012 y del Retiro para Adultos realizado en abril. Dos excelentes espacios para comenzar a involucrarse y aprender un poco mas acerca de la comunidad de desordenes sanguíneos.

**! Bienvenido Tom!**

Esta es una publicación para la Comunidad Latina de Hemofilia de Carolina del Norte y para todos aquellos interesados en crear un lazo de amistad e intercambio con esta Gran Familia Latina.



This is a publication for the entire Latino Community with Hemophilia living in North Carolina and for all those willing to establish a bond of friendship and exchange with this Great Latino Family.

### Calendario de Reuniones -Meeting Calendar-

Septiembre , 15-16  
Retiro Familiar de la Unión  
Latina  
Lugar por determinar

Sábado 20, Octubre  
Caminata por la Hemofilia  
"Hemophilia Walk"  
Crabtree Lake, Morrisville,  
NC

Las fechas y los lugares pueden cambiar.

Para mas información llama a Guillermo Sánchez:  
1-855-462-5286  
O escríbenos un email.  
[unión.latina@hemophilia-nc.org](mailto:unión.latina@hemophilia-nc.org)



### 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.

### Ejercicio y deportes rodeados de los sonidos de la fauna Africana.



La segunda reunión del 2012 del Grupo de la Unión Latina tuvo como escenario la extensa variedad de los animales que habitan África, uno de los continentes mas interesantes del mundo. Conforme las familias iban llegando al Hippo Beach (o playa de los Hipopótamos) se notaba el interés por comenzar el recorrido de aquel continente. Algunos de los asistentes no podían disimular su inquietud en cuanto a lo largo, y posiblemente cansado del recorrido. E incluso, para las personas con hemofilia, la inquietud de que un sangrado terminara con el recorrido. Por suerte y para ayudar a responder a estas inquietudes, el tema de la charla de ese día fue, precisamente acerca de cómo cuidarse y prevenir sangrados al

ejercitarse o realizar deporte.

Conforme la charla se refería a cada uno de las recomendaciones para antes y después de ejercitarse o realizar algún tipo de deporte, las preocupaciones de que apareciera un sangrado durante el recorrido por África fueron disminuyendo. Los participantes aprendieron la importancia de realizar algunos movimientos de calentamiento antes de comenzar a caminar distanciar larga, comprendieron la importancia de realizar pausas para no forzar hasta el sangrado las articulaciones y músculos involucrados en distintos ejercicios y deportes. Y se confirmaron la importancia de siempre realizar ejercicio, deporte, o cualquier actividad que implique movimiento físico acompañado de un bote de agua para rehidratarse. ¡En especial en temperaturas calientes como la que aquel día!

Gracias a Karla de **Baxter** por el apoyo para realizar este programa educativo.

# 1, 2, 3... por ti !

Tu o alguien de tu familia tiene  
**hemofilia, o algún otro**  
**Desorden Sanguíneo?**

**y además hablas español?**  
**Te estamos**  
**buscando!**

If you are a **Friend, Social Worker, Physician**, or just happened that you know someone from Latino America living with a **bleeding disorder**, tell them to contact us, we provide with a great educational and networking opportunities in their language: **Spanish**.  
Help us now and give the opportunity to change a life!!!

### Consejo Rápido

Mientras a mas temprana edad los niños con algún desorden sanguíneo se involucren en su tratamiento, mas rápido podrán tomar responsabilidad de mantener una buena condición de salud.

\* Deja que se involucren desde pequeños: que observen el proceso de reconstitución del Factor.

\* Asígnales pequeñas tareas dentro del proceso de reconstitución e infusión.

\* Que formen parte activa desde muy pequeños en el almacenaje adecuado de los medicamentos y del registro de las medicinas que se administran.

**!Muy pronto lo harán como parte de su vida diaria!**



# HNC Golf Tournament 2012

The weather, a tournament's worst enemy, behaved and it turned out to be a beautiful day for golfing! We held our 8th Annual Charity Golf Tournament on April 20th and were accompanied by some wonderful individuals.

The Preserve at Jordan Lake generously hosted our group for another year. The day quickly kicked off as golfers began to arrive. Starbucks Coffee served beverages to help everyone wake up before their long, hard day of golfing began.

Before heading out onto the holes, we all enjoyed delicious lunches, complements of JD's Tavern. Perry Parker, sponsored by CSL Behring, and Kathy Register, HNC's Treasurer and volunteer interim Executive Director, spoke before the golfers departed onto the green and thanked them for their support. The Women of the Moose at the Lexington Moose Lodge donated non-alcoholic drinks to keep our golfers hydrated. Julie Baker hitched rides in the golf cart to take pictures of the players and capture their swings on camera, all of which are on our Facebook page: [www.facebook.com/HemophiliaNC](http://www.facebook.com/HemophiliaNC)

Golfers began pouring back in just in time to fill up on some tasty wings provided by Apex Wings. Shortly after, the Preserve served dinner as families started to arrive. Drinks started to appear as people began to wind down from the day's festivities.

The raffle items included a signed Davis Love III Ryder Cup flag, packages from the Master's, foursomes at the Preserve and Chapel Ridge, and much, much more. Raffle tickets were selling like hot cakes this year and for good reason!

After drawing the raffle tickets and crowning winners with their prizes, we were left with one very important task...to thank everyone for their continued support. We gave a special thank



you to CSL Behring, who stepped in as our tournament sponsor for this year. From the golfers to the sponsors, we would not have been able to host our 8th Golf Tournament without this support.

- **1st Place** - Moore Printing: Curtis Hicks, Jay Hinton, Jimmy Turner & Mike Vaught
- **2nd Place** - Max Berliner (DrugCo), John Haf (DrugCo), Tom Linville & Bob Sherwood
- **3rd Place** - Kelly's NC Erosion Control: Todd Elwell, Joe Kelly, Dave Pelowitz & Richard Stroker
- **Most Honest Team** - Sheldon China & John Peretti
- **Closest to the Pin** - John Lack
- **Longest Drive** - Doug Piner
- **Longest Putt** - Harvey Gates
- **Beat the Pro Raffle Winner** - Bill McGee

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## Inhibitor Insights

# Wishful Thinking from Inhibitor Families

By Jo Schaffel

*“I would love to see a longer-lasting VIIa.”  
 “A medicine that would eliminate an inhibitor.”  
 “Products that don’t cause inhibitors in the first place.”*

Are any of these on your wish list for new or improved inhibitor products?

Wouldn’t it be great to have a fairy godmother (or a genie in a magic lamp) who could grant any wish? How about an inhibitor product that would last days or weeks instead of just a few hours? Maybe even one that didn’t have to be given intravenously?

In our real world, we don’t have fairy godmothers or genies (oh well), but there are scientists, doctors, and researchers who are working on some of the items on our wish lists.

### Wishes for... Faster-acting or longer-lasting factor

Factor products that last longer in the bloodstream are at the top of many inhibitor family wish lists. Advances in biotechnology are raising hopes that faster-acting or longer-lasting therapies and treatments for inhibitors will be available in the next few years.

Debbie Porter of California is one mother who’d like to see products last longer. “I mean long lasting,” she explains, “not just an hour or two more – I’m talking days or weeks.” Medically, inhibitor bleeds can mean days in the hospital coping with pain. And bleeds are often more frequent in inhibitor patients because of multiple target joints. A longer-lasting product would possibly reduce the frequency and help preserve the joints.

A bleed also means a child misses many days of school, or an adult misses many days of work. Dosing frequently for several days to heal a bleed can be tough, especially in children, who have trouble sitting still in the best of circumstances. Cicely, who has a son with inhibitors, would also like to see products that last longer than the ones currently available. “Longer-acting VIIa would be wonderful, especially for the inhibitor patients, like my son, who have joint bleeds every day.” She notes, “The hardest thing we face is keeping a very active boy immobile while healing, to prevent re-bleeding.”

Yes, life can be tough for inhibitor patients. The good news is that several companies are now working on longer-lasting recombinant factor VIIa. CSL Behring is testing a new recombinant product, rVIIa-FP, which

*Continued on page 14*

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## Inhibitor Insights *continued*

has a longer half-life than the only factor rVIIa product currently on the market: Novo Nordisk's NovoSeven®RT. A product with a longer half-life means that patients would need fewer doses of factor to stop bleeds, and the doses could be spread farther apart. Inspiration Biopharmaceuticals is also working on a recombinant factor VIIa, which is now in preclinical trials (not yet tested in humans).

Novo Nordisk is in phase III clinical trial of a faster-acting rVIIa product. It's designed to produce a stronger clot so a bleed can be stopped with fewer infusions.

### *Wishes for... New types of products*

How about a brand-new type of product—one that hasn't been on the market yet? Maybe one that works in an entirely different way from the products that are now available?

"I would like to see a new product that would be more effective during an inhibitor [bleed] instead of taking so many days or weeks for a bleed to heal," says Cazandra MacDonald, mother of two sons with inhibitors.

Inspiration Biopharmaceuticals is currently in the phase III clinical testing stage of a new recombinant porcine (pig) factor VIII, called OBI-1. It's not a bypassing product but is intended to treat hemophilia A with inhibitors. Porcine factor VIII is close enough to human factor VIII to participate in the coagulation process to form a clot, but different

enough that it escapes detection by most inhibitors to human factor VIII.

Novo Nordisk is also working on a new treatment method called Anti-TFPI, which is in phase I clinical trial. TFPI stands for tissue factor pathway inhibitor. It's a protein that stops or slows the formation of blood clots. Anti-TFPI blocks the action of TFPI, allowing coagulation to proceed even in the absence of factor VIII or factor IX. And best of all, it can be injected subcutaneously!

The new or improved products currently being tested hold much promise, but not everyone may be willing or able to change treatment regimens right away. Cazandra explains, "There would have to be some significant reasons to change...when you find a product that works, why change?" Cicely would keep an open mind about changing her regimen. Debbie might be willing to use a new or improved product: "If there was good science behind it...if it offered substantially better benefits and I thought it was safe."

### *Wishes for... Better access to care*

Unfortunately, many of the challenges facing families with inhibitors may not be fixed by new and improved products alone.

Your family may live far from a hospital or HTC, or the medical staff near you may have little or no experience with inhibitors. "We have to go to another state to monitor the inhibitor because their doctors have inhibitor experience," Cazandra explains. More treatment centers with staff trained in inhibitors would ease this burden.

The high cost of inhibitor products is another major concern. As medical costs skyrocket, employers and insurance companies are taking a closer look at their bottom line. They may start limiting access to certain (more expensive) products or discouraging the use of "newer" or what they consider "experimental" products. Employers may cut back on their employees' insurance coverage. But, says Debbie, "It would sure be nice to have [products] that more people could have access to."

### *Wishes for... Finally, a cure*

Of course, a cure for hemophilia or prevention of inhibitors tops everyone's list. Debbie explains, "Inhibitor patients have more joint damage, more hospitalizations...The top of my wish list would be medicines or therapies that cure hemophilia or eliminate the inhibitor."

As scientists continue to study the complex genetics of hemophilia, they hope to gain insights into who might be more likely to develop an inhibitor. We may be able to tailor treatments to prevent inhibitors in people who show a high risk of developing them based on their genetics. Or, if inhibitors do develop, specific treatments could be created for individuals based on their particular genetics or biochemistry.

Researchers are working on finding ways to cure or prevent hemophilia altogether. If we could replace the defective genes that are causing hemophilia with properly working genes, patients could eventually produce their own clotting factor. No bleeds, no inhibitors. A wish come true.

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## Medical College of Wisconsin Receives NIH Grant for VWD Studies

In March, the Medical College of Wisconsin (MCW) received a five-year, \$10 million National Heart, Lung, and Blood Institute Program Project Grant. This grant will allow researchers to continue genetic studies on patients with von Willebrand disease (VWD), the most common hereditary bleeding disorder estimated to occur in 1% to 2% of the population. Pediatric hematologist Robert R. Montgomery, MD, professor of pediatrics at MCW, senior investigator at the Blood Research Institute of the BloodCenter of Wisconsin, and pediatric hematologist at Children’s Hospital of Wisconsin, is principal investigator for the grant. He is a member of the National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC).

VWD and its subtypes are characterized by either quantitative defects (decreased amount) or qualitative defects (abnormal structure or function) in von Willebrand factor (VWF). Bleeding symptoms can be mild, moderate or severe, depending on the type. The investigators will use the grant to further research on 600 families to learn more about the genetic mutations and clinical factors that cause a deficiency of VWF.

“There is a lack of understanding of the genetic causes of low or abnormal VWF, and the molecular mechanisms involved in the disorder,” said Montgomery. “While a large number of individuals have low VWF with abnormal bleeding symptoms, it is not scientifically clear if this is a disease, or if VWF is a continuous risk-factor for bleeding. For many practicing physicians, the general understanding of this group of disorders has not been optimal, and how to evaluate and treat these patients has been unclear.”

Montgomery’s co-investigators at MCW and Children’s Hospital of Wisconsin are: Sandra L. Haberichter, PhD, associate investigator at the Blood Research Institute and associate professor of pediatrics; Joan Cox Gill, MD, professor of pediatrics and Director of Comprehensive Center for Bleeding Disorders at the BloodCenter of Wisconsin; Raymond G. Hoffmann, PhD, professor of biostatistics in pediatrics; Veronica H. Flood, MD, assistant professor of pediatrics; and Kenneth D. Friedman, MD, associate professor of medicine and Director of Hemostasis Laboratory and Medical Director at BloodCenter of Wisconsin.

In addition, there are seven primary clinical centers and more than 25 secondary clinical centers throughout the U.S. that recruit research subjects and send the samples to Milwaukee for the specialized testing.

The project grant mechanism is designed to support synergistic research, in which the funding of several interdependent projects as a group offers significant scientific advantages over supporting these projects as individual research grants. This multinational grant is facilitated by teamwork between the MCW, BloodCenter of Wisconsin and Children’s Hospital of Wisconsin, which oversee subcontracts to Queens University in Canada and University of Sheffield in the United Kingdom.

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## *New Consumer Assistance Grants Will Give States More Resources To Help Consumers Get And Keep Health Coverage*

### **Affordable Care Act grants have saved consumers millions**

Health and Human Services (HHS) Secretary Kathleen Sebelius today announced a new round of funding to support state-based Consumer Assistance Programs that help consumers who have questions or concerns regarding their health insurance. An HHS report released today also shows that hundreds of thousands of consumers have been helped by state consumer assistance programs funded by the Affordable Care Act – the health care law.

“The health care law is putting consumers, not insurance companies, in control of their health care,” said Secretary Sebelius. “Consumer assistance programs provide a valuable tool for consumers who have questions or concerns about their health insurance.”

Consumer Assistance Program (CAP) grantees, which can be state agencies or local non-profits contracted by a state, provide a wide variety of services for consumers. They can help consumers find health coverage and file appeals against health plans. For individuals unsure about their rights, Consumer Assistance Programs can educate them to take action. To provide better assistance with future requests, Consumer Assistance Programs are required to track consumer complaints to help identify problems and develop solutions.

In October of 2010, CAP grants were awarded to 35 states, the District of Columbia, and four territories. The report released today shows that from October of 2010 to October of 2011:

- CAP grantees directly assisted more than 200,000 consumers and reached hundreds of thousands more through outreach and education efforts.
- CAP grantees recovered more than \$8 million in direct savings for consumers and millions of dollars more in unquantifiable savings from better coverage.
- More than 75 percent of all cases closed by CAPs were resolved in the consumer’s favor.

The new funding opportunity announced today ensures that CAP grantees, whether operating in state agencies or as local non-profits, can continue to strengthen and enhance ongoing efforts in the states and local communities to protect consumers.

The grants will build on other programs and initiatives under the Affordable Care Act to help consumers make decisions about their care, including [www.HealthCare.gov](http://www.HealthCare.gov), where consumers can find health insurance options customized to their needs and location as well as other information about their benefits and rights under the Affordable Care Act.

*Source: News Release from [www.hhs.gov](http://www.hhs.gov), June 7, 2012*



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## Raising Medicaid Primary Care Rates: Next Steps for States

By Tricia McGinnis, M.P.P., M.P.H.

The Department of Health and Human Services (HHS) recently released long-awaited proposed regulations for implementing the Affordable Care Act's Medicaid primary care rate increase. Reimbursement rates for all types of health care services provided to Medicaid beneficiaries have historically lagged behind fees paid to providers treating Medicare beneficiaries or people with private insurance. As of 2008, Medicaid fee-for-service provider payments were only 66 percent of Medicare rates on average, with just five states paying rates close to the Medicare level.

Even Medicare has tended to underpay for primary care, a shortcoming addressed in the health reform law by a provision increasing Medicare payments for certain primary care services by 10 percent from 2011 through 2016. Not only is this increase expected to improve access to primary care, but there is evidence that such an increase can reduce Medicare spending over time.

To address primary care underpayment in Medicaid in 2013 and 2014, states must reimburse Medicaid primary care providers on par with Medicare rates for certain services, with the federal government picking up the cost of the increase. The increase aims to encourage more providers to participate in Medicaid, promoting access to primary care for current beneficiaries, as well as the 16

to 20 million individuals who will be eligible for Medicaid through coverage expansion in 2014. Research suggests that a Medicaid rate increase would also decrease inappropriate emergency room use.

The following are takeaways from the proposed rule:

**Provider eligibility.** States eager to use the rate increase to improve access and strengthen primary care will benefit from the broad approach to provider eligibility. Family medicine, general internal medicine, and pediatric medicine specialists and subspecialists recognized by the American Board of Medical Specialties will be eligible.

**Physician extenders.** Notably, physician extenders, such as nurse practitioners and physician assistants, will also be eligible, if service delivery is supervised by an eligible physician and properly billed under that provider's number.

**Covered services.** The proposed regulation seeks to include all primary care services specified in the statute, including services for which Medicare sets rates but does not cover. (The increased payment rates are based on the Medicare fee schedule and exclude the recent 10 percent bonus that went into effect in 2012 as part of the Affordable Care.) States are given discretion over whether to set

*Continued on page 18*



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## Raising Medicaid Primary Care Rates *continued*

a fixed annual fee schedule based on Medicare rates at the beginning of 2013 and 2014 or to make adjustments reflecting Medicare changes made during the year.

**Managed care.** Implementing the rate increase within managed care may present challenges. The proposed rule seeks to ensure that Medicaid health plans implement the increase uniformly and that primary care providers receive the full increase. States must modify health plan contract amendments to reflect these requirements. Health plans must accurately report expenditures eligible for 100 percent federal reimbursement to the states. Adjusting health plan capitation rates to reflect the rate increase will be methodologically complex. The proposed rule suggests an approach, but also provides flexibility for states to define their methodology and submit it to the Centers for Medicare and Medicaid Services (CMS) for approval.

Though the proposed rule is not final, states can take the following steps now to begin the implementation process:

- Provide input to HHS on the proposed rule at <http://www.regulations.gov>.
- Evaluate the fee schedule for alignment with Medicare site of service and payment regions.
- Identify strategies to document the rate differential.
- Gather information to identify potential methodologies for revising managed care capitation rates.

- Determine health plan reporting options for eligible expenditures.
- Explore strategies for confirming primary care provider “eligibility.”
- Identify primary care provider outreach strategies and engage relevant stakeholders, including state and local medical societies and non-physician provider groups.

Over the next few months, CMS will be working closely with states to answer remaining questions. For example, the proposed rule does not address how states using advanced payment methodologies—bundled payments for episodes of care, quality-based payments, case management fees, and global payments—would incorporate the rate increase. Since states across the country are exploring new payment models, further clarification from CMS would be helpful.

Still, states that have been awaiting federal guidance can move forward with implementation strategies. Getting Medicaid provider rates at parity with Medicare is a crucial first step for reducing health care disparities and strengthening the foundation of the nation’s primary care system.

*Source: “The Commonwealth Fund Blog”, May 24, 2012*



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**Where:** The North Carolina Zoo at Lakeside Picnic Area

**Address:** 4401 Zoo Parkway, Asheboro, NC 27205

**Occasion:** To enjoy lunch with your friends at Hemophilia of North Carolina, to visit the North Carolina Zoo, and to receive information about  
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