

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2013

## HNC's 2013 Hemophilia Walk

By Laura Meyers, Walk Event Manager

As HNC's 2013 Hemophilia Walk Event Manager, I am happy to report that the 2013 Walk ball is rolling! To date we have raised over \$30,000 for the October 19th event, and are happy to welcome our 2013 Walk Chair: Erica Cook of Jaden's Jewels.



Jaden's Jewels is honored with the Junior Droplet Award for their extraordinary support of the 2012 Walk.

The 2012 Walk was beyond successful, topping our goal by nearly \$25,000! The fundraising goal for this year has been raised to \$100,000. While we certainly want to meet our financial goal, we also hope to increase the number of participants, particularly new HNC members! If you are new to the organization, or have not yet been to an HNC event, the Walk is a terrific, family-oriented event to attend!

The Walk Kickoff is set for Sunday, August 25th at the Durham Convention Center in downtown Durham. We invite teams and team captains to join us for an insightful review of how to be a successful fundraiser, followed by fun at a Durham Bulls game!

We continue to work on sponsorships and would love to hear from those of you who have a company or organization that may be interested in sponsoring the Walk. Our thanks to our local corporate sponsors who have already

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## HNC's Support Outreach Advocacy Resources (SOAR) Program



### Spotlight: Cheri Clark

Having been a nurse for over 25 years, Cheri Clark was honored to attend the 29th Annual North Carolina School Nurse Conference in Chapel Hill. It is the premier conference for school nurses in North Carolina and attracts more than 500 participants a year.

Cheri was able to share her personal story and get information regarding von Willebrand Disease (vWD) into the hands of hundreds of school nurses so they could share it with the young women at their respective schools.

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On the Health Front  
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### Save The Date

**Blood Brotherhood Summer BBQ**  
HNC Office, Morrisville  
August 3, 2013

**HNC Family Retreat**  
Pine Knoll Shores – NC Outer Banks  
August 11-13, 2013

**HNC/HSC Teen Retreat**  
Charlotte, NC  
August 16-18, 2013

**HNC's 2013 Hemophilia Walk Kickoff**  
Durham Convention Center and  
Durham Bulls Athletic Park  
August 25, 2013

**NC Advisory Board for Bleeding Disorders**  
3rd Quarter Meeting  
September 6, 2013

**HNC Adult Retreat**  
Wilmington, NC  
September 7-8, 2013

**Blood Brotherhood Retreat**  
Wilmington, NC  
September 14-15, 2013

**Latin Union Family Retreat**  
Raleigh, NC  
September 14-15, 2013

**65th NHF Annual Meeting**  
Anaheim, CA  
October 3-5, 2013

**Inhibitor Family Camp at Victory Junction**  
Randleman, NC  
October 17-20, 2013

**HNC's 2013 Hemophilia Walk**  
Lake Crabtree County Park  
Morrisville, NC  
October 19, 2013



**Hemophilia of North Carolina**

260 Town Hall Dr., Suite A  
Morrisville, NC 27560  
(800) 990-5557  
info@hemophilia-nc.org  
www.hemophilia-nc.org

## MISSION STATEMENT

Hemophilia of North Carolina is a non-profit organization dedicated to improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research and supportive programs and services.

### Contact Numbers

#### Hemophilia of North Carolina

(800) 990-5557  
(919) 319-0014  
(919) 319-0016 (fax)

#### National Hemophilia Foundation

(800) 42-HANDI  
www.hemophilia.org

#### Hemophilia Federation of America

(800) 230-9797  
www.hemophiliafed.org

#### Community Health Charities of NC

(919) 554-3272 (Collect)  
www.healthcharities.org

### About This Publication

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

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

#### University of North Carolina At Chapel Hill School of Medicine

Campus Box 7016  
Physician Office Building  
170 Manning Drive  
Chapel Hill, NC 27599-7016  
Phone: (919) 966-4736  
htcenter.med.unc.edu

#### Wake Forest University Baptist Medical Center

The Bowman Gray Campus  
Department of Pediatrics  
Medical Center Boulevard  
Winston-Salem, NC 27157-1081  
Phone: (336) 716-4324  
Fax: (336) 716-3010

### Additional Medical Resources

#### Carolinas Medical Center Pediatric Hematology/Oncology

1000 Blythe Boulevard  
Charlotte, NC 28203  
Phone: (704) 381-6800

#### Duke University Medical Center Hemostasis and Thrombosis Center

DUMC Box 3422  
Durham, NC 27710  
Phone: (919) 684-5350  
htc.medicine.duke.edu

#### Presbyterian Blume Pediatric Hematology & Oncology Clinic

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

### Resource Information

**National Hemophilia Foundation**  
www.hemophilia.org

**Hemophilia Foundation of America**  
www.hemophiliafed.org

**American Pain Foundation (APF)**  
1-888-615-PAIN (7246)  
Hemophilia Chronic Pain Support Group  
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.

**Committee of Ten Thousand (COTT)**  
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www.cott1.org

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www.uneedpsi.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.

*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.*



## From the President

Dear Friends,

The past 15 months have been a tumultuous time for the HNC community. Our first full-time executive director, Sue Cowell, stepped down in March 2012, and all of us wondered how we would find someone to fill her shoes, and keep HNC on a steady course. We found an excellent steward for HNC, Tom Bennett, who tackled the enormous tasks of learning everything that HNC does – and that's a LOT – and maintaining the quality and variety of programs and services that HNC delivers. To his credit, and with the amazing efforts of Charlene Cowell and our outstanding volunteers, plus a highly successful Walk managed by Nicole Bailey, we can look back on a year where HNC continued to meet the needs of our community.

During this past year our community has also faced, and continues to face, challenges surrounding the implementation of the Affordable Care Act, and uncertainty about how support for the bleeding disorders community will be impacted in this state as a result. Tom Bennett did an exceptional job in advocacy, at both the state and national levels, and in coordinating activities with other health-related advocacy groups across North Carolina. His efforts awakened a desire in Tom to be involved in health care advocacy more fully than is possible as the HNC Executive Director, and so last month Tom decided to step away from HNC to pursue other opportunities in that area. Once again we find ourselves wondering – “What will happen to HNC and all of the programs we depend on?”

I want to reassure you that HNC is alive and well! HNC is financially sound and continues to deliver high quality programs and services. At the annual meeting this May, you elected a slate of dynamic and committed new and returning Board members. The Board is currently working to redefine the Executive Director and support positions to better serve HNC's goals and programs. We will be launching our Executive Director search within the next month, and we expect applicants of outstanding quality. We are fortunate to have the services of one of HNC's founders, Charles Register, who has volunteered as our interim Executive Director, and Charlene Cowell and Rita Brown continue their good efforts for HNC during this time of transition.

We are also very pleased to have Laura Meyers leading us through another successful Walk campaign this Fall.

Once again HNC faces change, and change can be scary – it's uncertain, unknown, and that makes many of us uncomfortable. We have faced change before and prospered; we will face it successfully again, because there are some things that do not change. HNC, all of us, all of you, are a community that is committed to each other – to meeting our needs, sharing our hopes, realizing our dreams of a full, rich, complete life for all who suffer from bleeding disorders and all those who love and cherish us. That type of community – OUR COMMUNITY – will always succeed.



*Steve Peretti*  
HNC Board President

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# Vegas Comes to Durham at the HNC Casino Night

Fortunately, what happens in Durham doesn't stay in Durham! Hemophilia of North Carolina hosted our 6th Annual Casino Night on March 5th at Bay 7 in Durham. It was a tremendous success with over \$41,000 in income tallied in just one night. The proceeds will be used to support programs and services throughout the state in an effort to provide opportunities for those affected by bleeding disorders.

The evening featured professional entertainment casino dealers from Casino Party Aces along with live entertainment by a quintet from the UNC Chapel Hill Jazz Band. In addition to the excitement at the craps, roulette, blackjack and poker tables, silent and live auctions took place over the evening. Through generous donations and hard work by the planning committee, we were able to offer some wonderful items, including an Asheville getaway, Richard Petty Driving Experience, collection of vintage china, and a unique antique wooden music box. The live auction was fast-paced and fun as George Miles whipped the crowd into a bidding frenzy!

For a donation, guests were invited to participate in a Grand Prize Raffle drawing. The lucky winner will enjoy a two-night stay in a cottage at the beautiful Chetola Resort at Blowing Rock. We would like to thank the resort for their generous donation.

Attendees were treated to a delicious palette of food provided by Catering Works. The cupcake pops were a big hit with the crowd! Everyone also stayed well hydrated with a terrific selection of wines and a wide variety of beer to fit every taste that was generously donated by Yellow Tail Wines, Tyler's Taproom, and an anonymous beer connoisseur.

As the clock wound down, those attendees who were lucky enough to have chips left over cashed them in for tickets and chances to win some great door prizes. Not many people left empty handed as a wide array of items were distributed to the crowd.

A very special thank you to our sponsors, guests, donors and volunteers who helped make the evening so successful. The HNC Board of Directors would also like to acknowledge the hard work and tireless effort of the planning committee that included Tiffany Holland, Ann Skinner, Tom Bennett and Charlene Cowell.



*Winning big at the tables!*



**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2013 HNC Casino Night:**

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# 9th Annual HNC Charity Golf Tournament

By Zack Strange

Hemophilia of North Carolina's 9th Annual Charity Golf Tournament was held on April 12th and the turnout this year was fantastic. The Preserve at Jordan Lake generously hosted our group for another year. The day sped along as volunteers worked hard on preparations as the golfers began to arrive. Starbucks Coffee provided beverages to help everyone catch their stride before hitting the links for what would turn out to be a wonderfully fun day of golfing for everyone involved.

The weather this year threatened to not cooperate with us as the skies let loose a rather impressive downpour right before the tournament was about to begin. The threat of bad weather, however, could not dampen the spirits of the golfers or volunteers. Everyone stood around talking with one another and enjoying the lunches provided by JD's Tavern in Apex. The skies soon cleared and, even though the course was still very wet, the golfers began to work their way out towards the staggered starting positions and kick off the festivities.

Tom Bennett, HNC's Executive Director, spoke before the golfers headed out to the links and thanked everyone for their support. Kedrion Biopharma donated water and sodas to keep our golfers hydrated. Julie Baker tagged along with the golfers 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).

As the golfers began to filter back to the clubhouse to check and compare scorecards, they were greeted by an impressive layout of food. Apex Wings provided the starters, and The Preserve at Jordan Lake laid out a sumptuous dinner sponsored by Bayer and CSL Behring. Many golfers were found digging into the spread as their families gathered with them after their action-packed day on the greens.

The raffle began soon after everyone got back to the clubhouse. Items provided this year included a Carolina Hurricanes picture signed by #59 Chad LaRose, a Carolina Panthers helmet signed by All-Pro running back and lead rusher #34 DeAngelo Williams, assorted gift cards totaling over \$200, brunch for two at the Washington Duke Inn and Golf Course, \$100 in gift cards to Kroger and many more fantastic items. And the raffle tickets did sell for obvious reasons!

After the raffle, the tournament winners were announced and awarded amazing prizes. The last order of business for the day was to thank everyone once again for their continuing support. We offered a special thank you to Pfizer Hemophilia who sponsored this year's wonderful event. We also thanked everyone else in attendance for their support, including the golfers and their families, with special thanks to our fantastic volunteers, who worked tirelessly to make 9th Annual HNC Charity Golf Tournament a rousing success.

Special thanks to our Golf Committee: Ben Barker, Matt Barnes, Tom Bennett, Charlene Cowell, James Fullam, and Jim O'Malley.



Having a ball at the Golf Tournament!

## And the Winners Are:

**1st Place:** Moore Printing (For the second year in a row!)  
Deny Buchannan, Jimmy Dropco, Jimmy Turner, and Mike Vaught

**2nd Place:** Kelly's NC Erosion Control  
Dustin Keasure, Joe Kelly, Dave Pellowitz, and Richard Stroker

**3rd Place:** Martin Eye Associates  
Pete Huff, Mike Morgan, Doug Piner, and Bill Zamboni

**Most Honest:** John Peretti

**Closest to the Pin:** Dave Pellow

**Putting Contest:** Tom Storrie

**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2013 HNC Charity Golf Tournament:**

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# HFA Symposium 2013

The Hemophilia Federation of America (HFA) held its 2013 Symposium between April 25-27th in Dallas, Texas. Hundreds of people from all over the country came together for an educational and life-changing weekend. Families, educators and advocates gathered to share experiences and information with one another.

HNC was well represented with two of our members taking part in panel sessions. Sharon Ingram, BS, HSBCP, was co-facilitator of the Partners/Spouses Rap Session; and Charlene Cowell, HNC's Operations and Member Services Manager, was co-facilitator of the session Building Communities of Women.

HNC's very own Judy Igelman was presented HFA's President's Award by Matthew Compton. Matthew gave a heartwarming speech about Judy's long-standing dedication to the bleeding

disorders community. Many of you may know Judy from her Ted-E-Bear Hospital program, which she has always generously volunteered to run at any bleeding disorders event. Her passion and high-spirit shines in everything she does. Congratulations Judy and thank you for all you do! Thanks to you, kids all over the country have new favorite teddy bears and an understanding of genes!



Judy Igelman with her HFA President's Award

HFA's Annual Symposium is a wonderful way to meet people from all over the country, enjoy educational sessions, and catch up with old friends! HFA awards over 100 travel scholarships for first-time attendees so keep your eyes out for 2014 Symposium information.

For more information about Hemophilia Federation of America and the HFA Symposium, please visit the HFA website at [hemophiliafed.org](http://hemophiliafed.org).

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## HNC 40th Annual Meeting

# 40 Years of Friendship and Opportunity

Beginning in 1973 as a loosely organized group of volunteers, the community of Hemophilia of North Carolina celebrated its 40th year at the HNC Annual Meeting on Saturday, May 4, 2013. The all-day meeting was held at the beautiful Greensboro Marriott Downtown. Over 120 people attended the event, which included many pertinent talks and a separate program track for children. As in the past, the HNC Annual Meeting was a great opportunity to meet some experts, share experiences with others, support families new to our community, and learn about the latest products available.

Early Saturday morning, our vendor exhibit hall was opened and a continental breakfast was served. The Annual Meeting was hosted free of charge to the HNC membership through the generous support of our sponsors and contributions from our community.

Our keynote speaker was Alice D. Ma, M.D., Clinical Associate Professor of Medicine in the Division of Hematology-Oncology

at the University of North Carolina School of Medicine. Dr. Ma presented “New Developments in Hemophilia Care”, providing attendees with critical updates related to their care.

After the morning break, Daysi Fardales, MSN from Pfizer Hemophilia, spoke about “Living a Healthier Lifestyle Through Fitness and Nutrition”. While Daysi was speaking in the main meeting room, Kristy Lee, MS and Certified Genetic Counselor from the UNC School of Medicine, led a breakout session to educate attendees about genotyping and ongoing initiatives.

Attendees also had the option to join our HOPE breakout session during this time. HOPE is one of HNC’s newest programs; the name stands for Help, Opportunity, Partnership, and Empowerment. The focus of HOPE is to improve the quality of life for families with children ages twelve and under with bleeding disorders. Gillian

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## HNC Annual Volunteer Dinner

The evening before HNC’s Annual Meeting was the occasion of the special invitation-only HNC Annual Volunteer Dinner. This was a chance for HNC to honor the many volunteers who have given so generously of their time and effort this past year.

Addressing the group was George McCoy, former HNC president and volunteer since HNC’s early days. George gave a moving account of his own personal history, and many experiences both good and not so good. He talked about the impact of volunteers and volunteerism in his own life, in the hemophilia community, and throughout the country. He believes that without volunteers there would be no progress in addressing the problems facing hemophilia in particular and humanity in general. Indeed, George himself is a volunteer with few peers. We were honored to have him as our guest and speaker for this evening.



*George McCoy captivating the audience once again.*

**HNC 40th Annual Meeting** *Continued from page 7*

Schultz, HOPE's volunteer Program Coordinator, facilitated this session.

The HNC Business Meeting took place in the early afternoon. Board Vice President Leonard Poe and Executive Director Tom Bennett gave the annual reports on the organization's finances and accomplishments over the past year. The last item of business was the election of the 2013-2014 Board of Directors. Six candidates were chosen as first-time board members, and three of the existing board were reelected. These nine will begin two-year terms beginning July 1; they will join four current board members who will return to complete the second year of their term. A special thank you was given to retiring board members Scott Andrews, Warren Ingram, Kathy Register, Maria Schnaith-Ivan, and Ann Skinner. Contact information and bios for all board members will be available shortly on the HNC website.

A Hemophilia Treatment Center (HTC) panel consisting of Steve Humes (Regional Coordinator for the Region IV-North Hemophilia Treatment Center Network), Sally Wright (UNC Chapel Hill), Anita Smith (Wake Forest Baptist), and Charmaine Bond (East Carolina University) spoke about the benefits of seeking treatment

at an HTC. The panel helped attendees to understand the process of visiting an HTC, what is offered, and how to make the most of their time there.

As the panel of HTC staff captivated the main audience, we offered breakout sessions for our SOAR and Blood Brotherhood Programs. Matthew Igelman, our Blood Brotherhood program Coordinator, and Jennifer Newman, Physical Therapist at UNC Chapel Hill, bonded with the Blood Brothers as they discussed issues related to men and bleeding disorders. The SOAR women, in the breakout room next door, could barely contain their laughter as they introduced themselves through an icebreaker. Led by Crystal Hoernlein, the SOAR women discussed the importance of a women's group and brainstormed about future plans.

Our final presenter was Johanna Gray, National Hemophilia Foundation's (NHF) Washington Representative, who spoke about one of the most popular topics, the Affordable Care Act. For

*Continued on page 9*

**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2013 HNC Annual Meeting:**

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 Walgreens Hemophilia Services

**Please welcome the new HNC Board of Directors Elected at the 2013 Annual Meeting**

Steve Peretti <i>(note 1)</i> President Durham, NC	Leonard Poe <i>(2)</i> VP & Advocacy Chair Burnsville, NC
Reid Coleman <i>(3)</i> Winston-Salem, NC	Erica Cook <i>(3)</i> Winston-Salem, NC
Mike Hoernlein <i>(2)</i> Charlotte, NC	Tiffany Holland <i>(1)</i> Concord, NC
Steve Humes <i>(2)</i> UNC Chapel Hill	Matt Igelman <i>(3)</i> Wake Forest, NC
Amy Shair Miller <i>(1)</i> Durham, NC	Guillermo Sanchez <i>(3)</i> Cary, NC
Sharon Sebolt <i>(3)</i> Durham, NC	Zack Strange <i>(3)</i> Efland, NC
Sally Wright <i>(2)</i> UNC Chapel Hill	

NOTES: 1. Reelected to a new 2-year term  
 2. Returning to complete 2-year term  
 3. New to the HNC Board

**AND THANK YOU TO RETIRING BOARD MEMBERS**

Scott Andrews • Warren Ingram • Kathy Register  
 Maria Schnaith-Ivan • Ann Skinner

Visit the HNC website at [www.hemophilia-nc.org](http://www.hemophilia-nc.org) for board member photos, bios, and contact information.

*HNC 40th Annual Meeting* *Continued from page 8*



*The Turtle Races: on your mark, get set, go!*

a subject that can be so daunting and confusing to some, Johanna did a marvelous job explaining the recent and upcoming changes to our healthcare through the ACA.

Our youngest attendees, ages 4-12, had the opportunity to get a first-hand look at reptiles while learning about these fascinating creatures' habits and habitats. Live turtle races were definitely the highlight of the children's day! Afterwards, Abrakadoodle came in to assist with a variety of arts and craft projects to ensure that no child left without something to commemorate their time at our 40th Annual Meeting.

Thanks to BioRx LLC., teens were involved in the Clot Shots program for the entirety of the meeting. Here they were introduced to the use of modern technology as a form of personal expression to patients living with a bleeding disorder. Working in groups, teens learned different aspects of production, including writing, filming, lighting, editing, and directing. At the end of the meeting, teens showed off their masterpieces to the rest of our attendees.

We closed out the meeting with our Vendor Visit Raffle, where almost everyone who stayed won a prize! After the meeting, attendees were welcome to enjoy a picnic at Barber Park, where we had the two essentials: food and fun games.



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## HNC's 2013 Hemophilia Walk

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committed their support: Accredo, Biogen Idec Hemophilia, Drugco Health, HPC International, Kedrion Biopharma, MedPro Rx, Pfizer Hemophilia, Novo Nordisk, and our Local Presenting Sponsor Grifols.

The 2013 Walk website is now open at [www.hemophilia.org/walk](http://www.hemophilia.org/walk) for more information and registration. Printed Sponsorship Packets, Team Captain Packets, and Volunteer Information are also available through HNC by calling 800-990-5557 or by emailing Laura at [laura.meyers@hemophilia-nc.org](mailto:laura.meyers@hemophilia-nc.org). See you in October!

## SOAR Program Spotlight

*Continued from page 1*

This type of outreach can make such a difference in the lives of the undiagnosed. As Cheri explained, "If I can help even one girl get a vWD diagnosis in a timely basis, my mission will be accomplished."

Before she met the women of SOAR, she'd only known one other woman with vWD: her sister. Her sister's diagnosis after a serious postpartum bleed caused Cheri to suspect that she must also have the disorder. She was often anemic and felt awful. After many years of being told that her bleeding was fibroid-related, she asked to be tested and discovered that she did indeed have vWD.

In Cheri's words, "After meeting the many other women of SOAR and hearing their stories, I felt empowered. I was on a mission to educate as many other women as I could on vWD, many of whom have suffered as I had, needlessly without an answer. SOAR is like one big family. We can all relate to each other and to the trials and tribulations of having a bleeding disorder. I know they are there to support me, as I am there to support them. I'm privileged to be a part of this wonderful group of women whose mission is to provide awareness about vWD and give information and support to those dealing with it."

Thank you for your commitment to the bleeding disorders community, Cheri!

*SOAR will again be forming a team for HNC's 2013 Hemophilia Walk so contact the HNC office or go on the Walk site to register as a walker under the SOAR Team.*

## 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

Matt and Christine Barnes

John and Patricia Bartlett

Meghan Cleinmark and all our friends at  
McLendon Clinical Laboratories at UNC Hospitals

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Sue and Charles Cowell

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Jeff Harper

Sue and W. Allen Heafner

Drs. David Howell and Sara Miller

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# UNC's Dr. Paul E. Monahan Honored by NHF

Dr. Paul Monahan, Associate Professor, Department of Pediatrics, Division of Hematology-Oncology of the University of North Carolina Chapel Hill was recently honored with NHF's Leadership in Research Award at the Third Annual Spring Soiree. The Soiree, a benefit for the National Hemophilia Foundation, took place on June 12, 2013 in New York City. In addition to Dr. Monahan, NHF honored three others who have made significant contributions to the bleeding disorders community.

NHF's Leadership in Research Award recognizes the outstanding achievements of researchers and physicians who have made critical advancements in improving treatment for hemophilia and advancing the field of bleeding disorders research. Dr. Monahan was acknowledged for his accomplishment in research, particularly his work in AAV vectors in gene therapy for factor IX deficiency. He was also honored for his dedication as a clinician and his commitment to volunteer work on behalf of the bleeding disorders community.

Hemophilia of North Carolina is grateful to Dr. Monahan for his outstanding service, and honored to have him as part of our community.



## UNC Lab Week Raises Over \$1700 for HNC!

By Meghan Cleinmark, MLS

Medical Laboratory Professionals Week is an annual celebration of laboratory professionals and pathologists who play a vital role in every aspect of healthcare. The last week in April is an annual time to recognize the professionals who work in the laboratories and behind the scenes. During Lab Week my committee for McLendon Clinical Laboratories at UNC Hospitals chooses a charity to support with the activities we plan for the week.

This year we chose Hemophilia of North Carolina. The laboratory personnel participated in a variety of activities including Cupcake Wars, Lab vs Lab Jeopardy, and a prize drawing with donations from around Chapel Hill and Durham businesses to raise funds for our assigned charity. This year McLendon Clinical Laboratories raised \$1730! We hope to have the same success in future lab weeks to come.



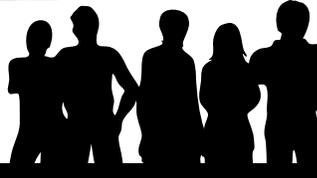
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**Edición  
Especial**

## Entrevista con Katherine Register

*Interview with Katherine Register*  
por Guillermo Sánchez / by Guillermo Sánchez

**Special  
Edition**

**K**athy, como la llaman sus amigos, fue nombrada Voluntaria del Año, reconociendo su compromiso y entusiasmo que entrega al realizar las actividades dentro de la Asociación. En esta edición tenemos el honor de presentarles la primera parte de una corta entrevista con esta extraordinaria esposa, madre y amiga.

**G(uillermo):** ¿Cuéntanos acerca del como comenzarte a involucrarte dentro de la comunidad de desordenes sanguíneos en Carolina del Norte?

**K(athy):** Mi esposo Charles, de 40 años, tiene hemofilia severa A (deficiencia de Factor VIII). Nosotros hemos sido miembros y trabajado para HNC, desde los años 70's, cuando la Asociación era todavía una filiar de la National Hemophilia Foundation. A finales de los 90's, ambos éramos parte en la mesa directiva de la Asociación y contribuimos a que ésta se constituyera como una identidad independiente. Después de un par de años alejada de la Asociación, regresé con mucho gusto para ocupar el puesto de tesorera dentro de la mesa directiva, función que desempeño desde el 2007. El año pasado, al salir Sue Cowell, fui nombrada directora ejecutiva interina por un periodo de tres meses. Mi esposo Charles desarrolló nuestra pagina en internet- la cual se ha ganado el premio a mejor portar de internet-, y continua a su cargo.

**G:** Parece ser que estamos ante una honorable miembro de HNC y que todo el trabajo que le has dedicado a la Asociación es invaluable. En verdad aprecio cuando la pareja de una persona con algún desorden sanguíneo, se involucra de tal forma en ayudar a nuestra comunidad, que comienza a ser una pieza esencial dentro del equipo de trabajo y contribuye a traer beneficios para sus miembros.

Me gustaría que ahora me platicaras sobre tus planes para el futuro. Espero, y casi puedo asegurar, que dentro de tus planes esta el continuar ayudando a nuestra comunidad, ¿estoy en lo correcto?

**K:** Mi compromiso en beneficio de la comunidad de desordenes sanguíneos es de por vida. Al separarme oficialmente del puesto de tesorera de la Asociación, continuare realizando esta función hasta que algún otro voluntario se haga cargo, o hasta que la mesa directiva me pida que deje de realizar este trabajo. Estoy segura que puedo hablar en lugar de Charles al decir que nosotros dos preferimos el trabajo "detrás del escenario" en vez de estar en el centro de atención, y no puedo imaginarme a ninguno de los dos dejando de apoyar a la comunidad.

**G:** Me alegra escuchar que tendremos el apoyo de Los Registers indefinidamente. El Programa de la Unión Latina ya ha sido benefi-

**K**athy – as her friends call her – was named HNC's 2012 Volunteer of the Year for her commitment and enthusiasm helping the chapter to achieve its goals. We are honored to show to all of you the first part of a short interview with this caring wife, loving mother, amazing woman, and friend.

**G(uillermo):** How did you become involved with the bleeding disorder community in NC?

**K(athy):** My husband of 40 years, Charles, has severe hemophilia A (Factor VIII deficiency). He and I have served as members or officers on and off since the 1970s, when HNC was still a chapter of the National Hemophilia Foundation. We were on the board and helped HNC to become an independent entity in the late 1990s. After a several-years' hiatus, I was pleased to get back on the board as treasurer since 2007, and as interim executive director last year for three months after Sue Cowell left. Charles single-handedly developed our award-winning web site, and continues to be our webmaster today.

**G:** You are an upstanding member of HNC and that all the work you have done for the chapter development is invaluable! I really appreciate when the partner of a person with bleeding disorder gets involved in our community to the point of being an essential piece within the task force that makes things happen for our benefit. I bet you and Charles inspire each other to continue with all this invaluable work. (By the way congrats Charles for stepping in and taking care of the HNC business as an interim Executive Director!!! You guys rock!)

Now, I would like to hear about your plans for the future. I am guessing and hoping that you are planning to stick around supporting our community for more years, right?

**K:** I am committed to the bleeding disorders community for life. While I have stepped off the board as of July 1 this year, I will continue to work at home as de facto Treasurer of the organization until someone else volunteers for the position, or until I am asked to step down. I think I can speak for Charles when I say that both of us prefer working "behind the scenes" rather than "in the limelight" and I do not foresee either of us ever stopping this work.

**G:** I am glad to hear we will have the Registers around indefinitely. The Latin Union program has already



ciado por su enorme experiencia y compromiso. Estoy seguro de que la mayoría de las personas estarán de acuerdo cuando digo que el estar “detrás del escenario” es el trabajo mas difícil , pero a su vez, el mas satisfactorio cuando se trabaja dentro de un equipo.

¿La segunda pregunta es acerca de tus experiencias en cuanto a tu relación con la comunidad Latina, ya sea a nivel profesional o personal?

**K:** Debido a que, tanto Charles, como yo somos jubilados, no tenemos experiencia reciente relacionada al contacto con la comunidad latina a nivel profesional. Sin embargo, a nivel personal, la comunidad latina es parte de nuestra familia; mi prima hermana es argentina y vive en Buenos Aires. Me da un poco de pena aceptar , que a pesar de esta relación con mi prima, mi español es muy poco, quizás debido a que no he tenido gran necesidad de utilizarlo y del buen nivel del idioma ingles por su parte.

**G:** ¿Cuál es tu opinión acerca de la decisión de HNC de crear un programa dirigido a las familias que hablan español dentro de la comunidad de desordenes sanguíneos?

**K:** Me llene de emoción cuando HNC inicio el Programa de La Unión Latina, que ha contado con el generoso apoyo de Baxter. Estoy muy orgullosa de éste y espero verlo crecer. Creo que no deberían de existir barreras políticas, culturales o de lenguaje, cuando se trata de acceder a un adecuado cuidado de la salud. Yo se acerca del temor y del estrés de tener a alguien con hemofilia dentro de la familia. Y me imagino que debe de ser el doble de preocupante al vivir dentro de una cultura diferente, en donde se habla un lenguaje que no es el tuyo.

**G:** Has Utilizado las dos palabras que mejor describen el sentimiento que afecta a la mayoría de las familias latinas que viven en Carolina del Norte: temor y estrés. Me interesa conocer la opinión de las personas que tienen algún familiar con desorden sanguíneo, en cuanto a lo que estarían dispuestos a realizar para obtener, no únicamente un trato de salud adecuado, sino el medicamento y dosis adecuados para mantener a su ser querido con vida y sin dolor. Me gustaría pedirte que te imaginaras que estas en un podio, frente a las familias latinas de nuestra comunidad de desordenes sanguíneos. ¿Qué les dirías para animarlos? y ¿Qué consejos les ofrecerías para que vivan mejor dentro de este país?

*benefited from your experience and commitment. I am sure most people will agree when I say that being “behind the scenes” is the hardest but most rewarding work when working on a team.*

*I guess the second question is about your exposure/contact with the Latino community either in a professional or personal level?*

**K:** *Because Charles and I are retired, we have no professional exposure of any kind at this time. On a personal level, the Latino community is a part of my family, because my first cousin is Argentinian, lives in Buenos Aires, and is Spanish-speaking. But I am a bit embarrassed to say that I speak very little Spanish. My cousin speaks English quite well, so I have not (yet!) had a compelling reason to learn Spanish, although I have been wanting to for quite some time.*

**G:** *What is your opinion on the HNC decision to create a program to serve the Spanish-speaking community living with bleeding disorders in NC?*

**K:** *I was very excited when HNC initiated the Latin Union program, which has enjoyed generous support from Baxter. I am very proud of it and hope to see it grow. There should be no political, cultural, or language barrier when it comes to getting good health care. I know how scary and distressing it is to have hemophilia in the family. It must be doubly scary living in a culture that is not your traditional one, and which uses a language not your own.*

**G:** *You have just used two of the words that better describe the feeling that is affecting most of the Latino families living in NC: scary and distressing. I am always looking for people who know what a family member of someone with bleeding disorder would do in order to obtain not just good health care but the right treatment to keep their beloved one alive and out of pain. So I would like you to imagine that you are standing in a podium in front of Latino families living with someone affected by a bleeding disorder. What would you say to them to cheer them up? And what advice would you have for them (how to “survive” in this country, strategies to cope, etc.)?*



2

**Calendero de Reuniones / Meeting Calendar** · Sábado, Junio 22, Bienvenido Verano, Concord, NC  
· Septiembre 14 y 15, 3rd Retiro Familiar del Grupo de La Unión Latina. Para mas información llama a Guillermo Sánchez: 855-462-5286 ó escribenos un email [union.latina@hemophilia-nc.org](mailto:union.latina@hemophilia-nc.org)

**K:** ¡Antes que nada necesitaría de un interprete! Les diría dos cosas:

1. Nuestro mayor reto, ya no son la ciencia y tecnología para el mejor tratamiento de los desordenes sanguíneos, ahora el reto es obtener el acceso a estos cuidados de la salud. Y desafortunadamente el acceso a la salud se ha convertido en un asunto político. La discriminación y el temor son causados por la ignorancia y el malentendido. Y aunque siempre hay periodos políticos que son peores que otros, actualmente estamos enfrentando tiempos difíciles.

La Reforma de Salud (Affordable Care Act-ACA) ofrece esperanza en los años que vienen para la nuestra comunidad. A pesar de lo que actualmente vivimos en nuestro Estado—burocracia que trae retroceso, así como discriminación— la mayoría de los Americanos son gente de compasión. La historia nos lo demuestra: El péndulo se balanceara de nuevo y la actitud de apoyo, que es parte de nuestra naturaleza, continuara presente dentro de las instituciones a nivel local y nacional. Mientras tanto, nuestra comunidad debe de permanecer unida y ayudarnos mutuamente para enfrentar estos momentos difíciles.

2. Desde que conocí a Charles en 1970, el progreso, en cuanto al tratamiento de los desordenes sanguíneos se refiere, ha sido extraordinario —incluso para las personas con inhibidores, lesiones musculo esquelético, enfermedades de la sangre, y especialmente

**K:** First of all, I would need a translator! I would say two things:

1. Our biggest challenge is no longer the science and technology of treating bleeding disorders, it is access to care. It is unfortunate that access to care has become such a heated political issue. There is a lot of ignorance and misunderstanding, which have become a foundation for fear and discrimination. Of course we see some political eras which are worse than others—but we are in the middle of a tough time right now.

Yet, the Affordable Care Act (ACA) offers promise and hope in the years to come. Despite what we are seeing now in North Carolina --- a sometimes horrifying bureaucracy and political push-back, as well as discrimination--the majority of Americans are compassionate people. As history is our guide, the pendulum will swing and the succor that is a part of our nature will continue to become institutionalized at the local and national levels. Meanwhile, we as a community must band together and help each other through this phase.

2. The progress I have seen in treatment of bleeding disorders since I met Charles in 1970 has been miraculous—even for people with inhibitors, musculo

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para las mujeres con algún tipo de desorden sanguíneo. Y aún, están por venir nuevas opciones de tratamiento que cambiaran definitivamente—y para su beneficio— a nuestra comunidad. Cambios que van desde la eficacia en la disminución de sangrados a la cura de enfermedades infecciosas, y de inventos que ayudaran a mejorar la movilidad y la salud en general. Hoy en día a un bebe nacido con algún desorden sanguíneo le espera un futuro brillante. Yo aún sueño con el día en que puedan ser curados los desordenes sanguíneos, que se puedan crear nuevos, y saludables extremidades utilizando células madre. Espero vivir (tengo 61 años) para verlo. Muchos de ustedes de seguro lo harán.

**G:** La Comunidad Latina de Desordenes Sanguíneos puede atestiguar acerca de la compasión y hermandad entre las familias que enfrentan esta condición de salud sin importar nacionalidad. Nuestras familias latinas en verdad se sienten parte de la comunidad de HNC. Es mucho mas sencillo adaptarse a otra cultura cuando tienes a alguien que te guie y te apoye en tan distintos sistemas político y de salud.

No te pierdas la parte final de esta entrevista en nuestro siguiente numero de The Concentrate – Otoño 2013– y entérate de las sugerencias que Kathy ofrece a todas las parejas de personas que padecen algún desorden sanguíneo!

*skeletal injury, and blood-borne diseases and especially for women with bleeding disorders. And there is about to be another explosion in treatment options that will change life forever for our community--all for the better--from mitigating our clotting problems, to curing infectious disease and inventions that will help with mobility and general health. A baby born today with a bleeding disorder faces a bright future indeed. I dream of the day that we can cure bleeding disorders, and clone new, healthy limbs with stem-cells. I may see that in my lifetime (I am 61). Many of you surely will.*

**G:** *The bleeding disorders Latino community in NC can attest to the compassion and kinship between families dealing with a bleeding disorder regardless of nationality. We really feel part of the HNC community. It certainly eases the adaptation into a new culture when you have someone that has your back and can guide you through such a complicated health care system and politics.*

4

*Don't miss the final part of this interesting dialogue in the next issue of The Concentrate – Fall 2013 – and find out what helpful suggestions Kathy has to offer to all the partners of people living with bleeding disorders!*

### Baxter's vision is a life without bleeds



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**Pursuing life without bleeds**

Learn more about Baxter resources and support at [ThereForYou.com](http://ThereForYou.com).

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# Upcoming Events

Information and registration forms for upcoming events will be provided by mail and available online soon but please feel free to call the office for additional information. All events are provided free of charge to HNC members.

## ***HNC Blood Brotherhood Summer BBQ***

**August 3**

The Blood Brotherhood is having a Summer BBQ! Come join the fun, food and great company. A traditional pork BBQ will be served, along with some tasty sides. The event is open to all adult men with bleeding disorders and their spouse/partner. The event will be held on Saturday, August 3rd, from 1-4pm at the HNC Office in Morrisville (Chamber of Commerce Building): 260 Town Hall Drive, Suite A, Morrisville, NC 27560. Please RSVP by calling the HNC office at (800) 990-5557 by July 20th.

## ***2013 HNC Family Retreat***

**August 11-13**

It's almost time for our annual Family Retreat, come out and join us at the Outer Banks! It will take place August 11-13th at the Trinity Center in Pine Knoll Shores, NC. We invite families with

children who are affected by a bleeding disorder to join us for a fun-filled, educational retreat at the beach. Recommended ages of the children are between 4 and 12 this year. We'll have an opening night full of fun and games with an opportunity to meet other families in the community. There will also be a talent show so be sure to bring anything you might need to show off your skills!

## ***2013 HNC/HSC Teen Retreat***

**August 16-18**

Calling all teens! Hemophilia of NC and Hemophilia of SC will be pairing for yet another exciting and adventurous Teen Retreat! We'll be heading to Charlotte, NC on August 16th-18th. We are very happy to have the CEO Program back again this year. The program includes a teen track and a separate parent track. Teens (ages 13-18) are encouraged to bring a friend or sibling along in the same age range. During the CEO program, teens will develop skills in career planning and financial independence. This program is open to teens with bleeding disorders or teens whose parents or siblings have a bleeding disorder. One parent/guardian per family is required to attend the program.

## ***2013 HNC Adult Retreat***

**September 7-8**

HNC is happy to announce that our 2013 Adult Retreat will be held September 7-8th at the Hilton Riverside in Wilmington! This retreat is available to adult members (age 21 and older) with a bleeding disorder or parent(s) of a child with a bleeding disorder. We will learn valuable information as Inalex Communications runs an all-day program on Saturday, and then you'll have the chance to reflect at the beach on Sunday!

*Also, save the dates for these upcoming retreats:*

## ***2013 Latin Union Family Retreat, Raleigh, NC***

**September 14-15**

## ***2013 Blood Brotherhood Retreat, Wilmington, NC***

**September 14-15**

Check the HNC website as these dates approach for more information.



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## Genotyping for Progress

# My Life, Our Future Aims to Unlock Hemophilia

During the past 20 years, advances in hemophilia treatment, including recombinant factor therapy, have allowed people with hemophilia to take greater control of their disorder. While the goal of safe and effective treatment through DNA technology has been realized, there is still much to be done to improve knowledge about the connection between the genetic cause of hemophilia and its management.

At the National Hemophilia Foundation's (NHF's) 64th Annual Meeting in November 2012 in Orlando, Val D. Bias, CEO, announced the launch of My Life, Our Future, a program that will help people with hemophilia and their families understand the unique aspects of their bleeding disorders by offering them free or low-cost genetic testing, also known as genotyping. The initiative is the result of a partnership between NHF, the American Thrombosis and Hemostasis Network (ATHN), the Puget Sound Blood Center (PSBC) and Biogen Idec Hemophilia. Genotyping may provide individuals and their physicians with insight into bleeding severity, inhibitor risk and carrier status, which can help improve their knowledge of the disorder and their care. It will also generate data that may advance scientific research on hemophilia and potentially lead to new treatments in the future.

## What Is Genotyping?

Genotyping is the process of identifying the specific genetic mutation responsible for an individual's disorder, in this case, hemophilia. "DNA is extracted from the blood to determine the factor VIII or IX sequence," says Barbara Konkle, MD, medical director for the Hemostasis Reference Laboratory, and director of clinical and translational research at PSBC. "This is then compared to normal factor VIII or IX sequence to identify the specific mutation."

Because of the large number of mutations associated with the disorder, genotyping is especially valuable in hemophilia. "There are more than 2,500 identified mutations for hemophilia A and more than 1,000 for hemophilia B. This

is in contrast to many other genetic disorders where one mutation is always responsible," says Marion Koerper, MD, medical advisor to NHF. Genotyping can identify the specific genetic mutation causing hemophilia in up to 98% of individuals who have hemophilia A and more than 99% of individuals who have hemophilia B.

## The Benefit to Patients

One of the many benefits of genotyping for hemophilia is its potential to predict inhibitor risk. Extensive research has already suggested that certain mutations are associated with higher risk for inhibitor formation. For example, in severe hemophilia A, individuals with inversion mutations or large deletions may have a higher risk of developing an inhibitor. Genotyping may also provide information about bleeding severity, which varies widely even among individuals with the same type of hemophilia. Identifying patients' genotypes may help physicians individualize treatment plans for them in the future. "If physicians can better understand someone's bleeding pattern or inhibitor risk, they can modify the therapy and care in an effort to provide the best outcome for the patient," says Konkle.

Moreover, these tests can also identify carriers, aid in early family planning, and possibly improve outcomes during childbirth and after delivery. "If a woman knows she is going to have a child with hemophilia, she and her family can better prepare for delivery and care," says Bias, who has hemophilia B and has been genotyped. He notes that genotyping has been a valuable tool for his extended family. The women in his family were genotyped when considering pregnancy. Genotyping has allowed them to embrace their family's bleeding disorder, Bias says.

## Addressing a Long-Unmet Need

Despite the benefits of genotyping, a survey of healthcare providers conducted by ATHN in October 2012 shows that only 20% of people with hemophilia in the US have

*Continued on page 18*

## Genotyping for Progress

*Continued from page 17*

been genotyped. The majority of respondents cited the cost of testing and insurance coverage restrictions as the main barriers. But the community's interest in genotyping is high. In a 2012 survey of more than 1,000 hemophilia community members conducted by NHF, more than 75% said they would take advantage of free or low-cost genotyping if it were available. My Life, Our Future addresses this obstacle and will eventually enable most people with hemophilia in the US to be genotyped at no or very low cost.

“For the past 15 years, we in the hemophilia community have been advocating for widespread access to genotyping for patients and carriers, but until now, the combination of resources and expertise was not available,” says Glenn Pierce, MD, PhD, senior vice president, global medical affairs for Biogen Idec and chief medical officer of Biogen

Idec Hemophilia. As a two-time past president of NHF's board of directors, Pierce remembers when NHF's Medical and Scientific Advisory Council (MASAC) passed a resolution in 1999 recommending genotyping as part of comprehensive care for individuals with inherited bleeding disorders. MASAC also recommended that NHF identify funding sources to make the service widely available. In 2003, a resolution was introduced in Congress to increase funding for research for bleeding disorders and facilitate genotyping, but it was not enacted. In 2005, the Centers for Disease Control and Prevention provided access to genotyping to a subset of patients as part of a study of inhibitors, but was unable to offer a national genotyping program due to logistical and funding challenges.

My Life, Our Future has been made possible through the collaboration of four leaders in the hemophilia community, each of which plays a crucial role in the program. ATHN, a not-for-profit organization representing more than 130 hemophilia treatment centers (HTCs), is ensuring the collection and secure storage of data and preparing HTCs to implement the service. NHF is educating patients and the community about the program through its chapter network and resources. PSBC, a state-of-the-art laboratory and research institution with expertise in hemophilia mutation analysis, is conducting the secure genetic testing and analysis. Biogen Idec Hemophilia, a biotechnology company committed to empowering people with hemophilia, is providing funding and scientific expertise for the partnership through at least 2014. Thereafter, the project may be extended to provide greater access to those affected by hemophilia. In November 2012, MASAC adopted a recommendation that all individuals with hemophilia and their affected family members participate in My Life, Our Future.

### My Life, Our Future: How It Works

The goal of My Life, Our Future is to genotype as many people in the US affected by hemophilia as possible. To ensure a smooth national rollout, the program is being

*Continued on page 19*

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## Genotyping for Progress

*Continued from page 18*

piloted in spring 2013 in at least 10 HTC's that will offer free or very-low-cost genotyping to existing patients.

Once the results from the pilot sites have been reviewed and any needed adjustments made, the genotyping service will be expanded to other HTC's across the country. Plans are to eventually expand the service to potential carriers.

During the pilot phase and after, individuals with hemophilia A or B who want to access the genotyping service will only need to visit their participating HTC for a blood test. The HTC will send the blood sample to PSBC's specialized hemophilia laboratory for genetic analysis. PSBC will then send a clinical report summarizing the test results to the HTC where the test was done. The patient's treating physician will then share the screening test results privately with his or her patient. This report will be stored in the individual's HTC record and in PSBC's secure laboratory information system. The clinical report will not be shared with insurers, employers or other parties. It will be up to patients whether they want to share the report with others, including family members. The program will adhere to best practices, and all state and federal laws designed to protect the privacy of patients, including the Health Insurance Portability and Accountability Act (HIPAA) and the 2008 Genetic Information Nondiscrimination Act (GINA).

### Furthering Scientific Research for Future Generations

In addition to receiving results that could improve the management of their hemophilia, participants will have the option to simultaneously support scientific research by making their de-identified genetic data and samples available to researchers. At the time of the test, patients will be asked to provide consent to allow their data to be entered into the ATHNdataset, a secure community resource that is now supported by more than 130 HTC's. Patients can also consent to have their blood sample and DNA stored in a research repository at PSBC. MASAC recommends that individuals "strongly consider agreeing to have their de-identified mutation results added to the ATHNdataset"

to further research and scientific understanding of the relationships between genotypes and clinical characteristics, called phenotypes.

In the future, scientists and researchers at academic institutions or drug discovery companies may apply for access to the data or samples through ATHN to support scientifically sound research projects. ATHN's review committee will screen these applications to determine the feasibility and scientific validity of each project. No organization, including Biogen Idec Hemophilia, will be given preferential access to the data.

Further, neither ATHN nor researchers will ever have access to patient names or any other information that could be used to identify an individual, or his or her family. "The patient's identity will remain strictly confidential. Data and samples will be labeled only with a code number," says Diane Aschman, MS, president and CEO of ATHN.

Although individuals who do not wish to contribute their data or samples for research can still be genotyped, the hope is that most patients will consent to their data and blood sample storage, knowing it could help future generations of people with hemophilia. A list of approved research projects and the studies conducted using the research will be made available to the public.

"This is an opportunity to pool the unique information that each of us possesses to advance the scientific understanding of hemophilia," Bias says.

Information for this article was provided by the National Hemophilia Foundation, the American Thrombosis and Hemostasis Network, the Puget Sound Blood Center and Biogen Idec Hemophilia.

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(<http://www.hemaware.org/story/genotyping-progress>)

# Medicaid and Bleeding Disorders

By Kadesha Thomas Smith and Marla Feinstein

Medicaid has long been regarded as the safety-net health insurance program for low-income individuals and families, seniors and those with disabilities. As the nation's largest public health insurance program, it covers roughly 60 million people and is funded by federal and state dollars. The percentage of federal vs. state funding varies by state.

When the Patient Protection and Affordable Care Act (ACA) was signed into law in March 2010, it included a provision mandating all states to expand their existing Medicaid programs to include all US citizens up to age 65 with incomes below 138% of the federal poverty level, which is \$14,856 per year for an individual or \$30,675 for a family of four. This mandate was intended to expand eligibility primarily to childless adults, a population that does not qualify for

coverage in most states. Currently, Medicaid covers people based on the state's income eligibility criteria.

In June 2012, the US Supreme Court ruled that states cannot be mandated to expand their Medicaid programs. However, states that choose to expand will receive additional federal funding to support new enrollees.

Starting in January 2014, members of the bleeding disorders community whose incomes were previously considered too high for Medicaid may be eligible. "Expanding Medicaid could potentially allow more vulnerable members of the population to participate, because eligibility will not be linked solely to disability status," says Michelle Rice, director of public policy for the National Hemophilia Foundation (NHF).

*Continued on page 21*

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# Medicaid and Bleeding Disorders

Continued from page 20

After age 18, childless adults are too old to qualify for the state's children's health insurance programs for low-income families. To remain on Medicaid, they must meet the state's criteria for disability. "Meeting a state's definition of disability is not always easy, and often varies from one instance to another," says Rice. "Medicaid expansion has the potential to prevent individuals from falling through the cracks."

As of March 2013, 25 states plus the District of Columbia planned to expand their Medicaid programs. Two others are leaning toward it, according to The Advisory Board Company, a healthcare research and consulting firm. Fourteen states have chosen not to expand coverage, and the rest are undecided. The federal government has stated it will finance a majority of the cost of expansion, including 100% of the costs in 2014–16 for individuals "newly eligible" (not previously eligible in their state). Beginning in 2016 this

amount will be reduced yearly, ultimately ending at 90% by 2020.

Expanding Medicaid would allow more people with bleeding disorders to access coverage. "There are clear differences in healthcare patterns between people with the same illnesses," says Rachel Garfield, PhD, senior researcher and associate director at the Kaiser Family Foundation's Commission on Medicaid and the Uninsured. "People with Medicaid are more likely to see a doctor, less likely to report problems," she says. "Coverage makes a difference."

NHF's public policy team often receives calls from individuals who either forgo treatment or use the emergency room as a primary provider, due to their inability to access healthcare coverage. Neither situation is recommended or ideal.

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## Medicaid and Bleeding Disorders

*Continued from page 21*

However, some Republican governors argue that simply expanding Medicaid without major Medicaid reform may not improve access to care and may make it even more difficult for states to provide adequate care. “Expansion without reform is not responsible and would bust the state budgets,” states a letter sent to President Barack Obama by GOP governors Bob McDonnell of Virginia and Bobby Jindal of Louisiana.

“The money piece is significant in certain states,” says Amy Lischko, DSc, associate professor of public health and community medicine at Tufts University School of Medicine in Boston. Healthcare already competes with other priorities for state funding, including education and public works. “Even though the federal government is paying most of the bill, many states are strapped for funding following the recession.”

Throughout 2013, states will be weighing the options and making a decision about expanding their Medicaid programs. Rice foresees some of the opposing states changing their decisions. “States will be facing pressure not only from patient populations, but also from hospitals to expand,” she says. Those that do not expand Medicaid will see costs rise elsewhere, Rice warns. “The care people do receive will be classified as uncompensated, which often makes care less affordable for everyone.”

People with bleeding disorders should keep a close eye on these changes. NHF’s public policy team will continue to keep you informed. Look for updates posted on NHF’s Web site and in eNotes, its electronic monthly newsletter.

Published on HemAware, April 11, 2013  
(<http://www.hemaware.org/story/medicaid-expansion>)



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