

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2013

2012 Holiday Celebration Rocks!

HNC's December 1st Holiday Celebration lacked snow and reindeer, but in every other respect, it was a holiday hoot with all the trimmings – including a dynamic appeal to use the holidays as a time to rededicate ourselves to helping others who are less fortunate. After all, the theme was “A Little Help Can Make A World of Difference.”

Approximately 200 people attended the festive event, which was held at the Hilton University Place in Charlotte. Guests heeded HNC's call to bring toothbrushes and toothpaste for African children with bleeding disorders, and as a result of their generosity, hundreds of youngsters will have the means to maintain good oral health.

Barry Haarde, a bicyclist who has recently ridden all the way across America for the international charity “Save One Life,” gave a moving account of his family's struggles with bleeding disorders during the “Bad Blood” era and in the years that have followed. Despite his own illness and grief, Mr. Haarde expressed an iron determination to prevail

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A young lad enjoying his turn with Santa Claus.

2012 Hemophilia Walk Breaks Record in NC

Everyone was moving and grooving, laughing and clapping. I looked out at the crowd and thought, “That’s the main thing. They’re having a ball!” – TVB



Some walk and some go faster, but all have fun.

The 5th Annual North Carolina Hemophilia Walk, which was held Oct. 20 at Lake Crabtree County Park, proved to be a triumph. More than 1,000 participants attended the Walk, and HNC raised more than \$106,000, which far exceeded the event goal of \$80,000. On top of that, it was a perfect day for the event, and everyone seemed to revel in the beautiful weather and a universal spirit of fun.

This year's featured performers – the hip, contemporary dance troupe JecoreiOgraphy – did an outstanding job of energizing everyone. The DJ picked just the right music to

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

Save The Date

Applebee's Flapjack Fundraiser
For Hemophilia of NC
1240 US Highway 29
Concord, NC
8:00 a.m. to 10:00 a.m.
Saturday, January 19, 2013

Advocacy Committee
Conference Call, 7 pm
Tuesday, February 5, 2013

HNC Advocacy Day
N.C. General Assembly, Raleigh
February 20, 2013

NHF Washington Days
Arlington, VA
Feb. 27-March 1, 2013

Advocacy Committee
Conference Call, 7 pm
Tuesday, March 12, 2013

NC Advisory Board
For Bleeding Disorders
Q1 Meeting
March 15, 2013

HNC Casino Night Fundraiser
Bay 7, Durham, NC
Saturday, March 30, 2013

HNC Golf Tournament
The Preserve, Cary
Friday, April 12, 2013

HNC Annual Meeting
Location TBD
May 4, 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

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
htcenterl.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

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)
1-800-488-2688
www.cott1.org

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

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

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

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

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

To amend a phrase by Charles Dickens, this is the best of times and the most challenging of times. As the bleeding disorders community braces itself for a new year, let's count our blessings but also resolve to work together on the challenges that await us in the months ahead:

Blessings & Challenges

(01) However you may feel about the outcome of the November elections, one thing is clear, the Affordable Care Act (Obamacare) is here to stay, and despite all its flaws and shortcomings, the ACA is a step in the right direction for the bleeding disorders community. Our job now is to make sure that North Carolina gets the details right. Whether the state runs it or the Federal Government runs it, we want an efficient and effective Health Benefits Exchange. It should feature a broad definition of essential health benefits that preserves choice and meets the unique needs of the bleeding disorders community. We also want our state legislature to expand Medicaid to 138% of the federal poverty level. Persuading our lawmakers to do that will be a big job, and you can help via our Advocacy Day scheduled for February 20 in Raleigh. (Please see Leonard Poe's article elsewhere in this edition.)

(02) "Industry," which is composed of pharmaceutical, specialty pharmacy and home care companies, puts a lot of money into Hemophilia of North Carolina – no less than 70% of our operating budget. That's the blessing and we should all be thankful for the generosity of these companies. The challenge is for HNC to maintain its independence and to continue to assure that we always put the best interests and privacy of our members first. In terms of privacy, we zealously guard your names and contact information. We've also developed and published a code called "Standards for Industry and Industry Agents" that sets clear boundaries as to what industry agents can and cannot do at our events. In terms of greater financial independence, we are looking at alternative sources of income such as our new car/vehicle donation program. In the months ahead you'll be hearing more about a bequest program, enhanced participation in Community Health Charities, and on-line sales of donated goods.

(03) We are blessed with a staunch group of volunteers who step forward and unselfishly serve the rest of the community. They've got jobs, family obligations and the hard task of managing their own illnesses or those of a loved one, yet they make time for others and help a very small HNC staff plan and manage the great array of events we host. That's the blessing. The challenge is that we need more such volunteers

to sustain our operations and help us break new ground in service, community outreach and fundraising. You know what you get from HNC, but do you ever ask yourself, "What am I giving back?" In the spirit of the holiday season and a looming new year, I challenge you to step forward and take your place among those who choose to go beyond minimums and help others. Regardless of who you are, where you live or what your talents include, HNC could use your help.



I'll close by counting a blessing and a challenge of my own. My blessing is the privilege of working for all of you and your children. I've been here at HNC for approximately six months, and getting to know you and your families is the best part of my job. My challenge is to run an organization that meets your needs and deserves your loyalty. It's a big job and I'll stay on it. Your help in the year ahead can make all the difference.

Warmest regards, Tom Bennett

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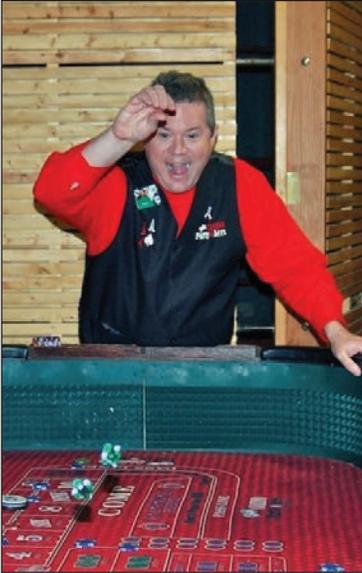
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Hot dice, big fun!

Hearts for Hemophilia Is March 30

Mark your calendars – Saturday, March 30, 2013 – for our most awesomely fun evening of the year: Casino Night 2013!

Be prepared to bring relatives, friends, and acquaintances and “dress to the nines” as Hearts for Hemophilia Casino Night returns to Durham’s American Tobacco Historic District and its most “unique and sought-after event space” – Bay 7 at the American Tobacco Campus. Enjoy Bay 7’s

“urban chic” design which includes exposed brick walls, hardwoods floors, steel girders, a balcony area and water feature.

Your ticket buys you a sumptuous feast accompanied by wine, beer, and beverages AND \$10,000 of “funny money” to gamble the night away. Casino Party Aces provides professionally operated Black Jack, Craps, Roulette, and the ever-popular Texas Hold ‘em, all for a good cause.

Bid for terrific prizes in our silent and live auctions. When the last table calls it a night, cash in your “funny money” winnings for raffle tickets for our evening-ending raffle.

For more information, call the HNC office at 1-800-990-5557 or be watching our website www.hemophilia-nc.org for registration information, starting early next year.

You won’t want to miss this event. Tickets and “Captain’s Tables” make terrific gifts for any occasion.

Don’t Miss HNC Advocacy Day!

With the 2012 elections behind us, we have a lot of work to do on health care reform.

Hemophilia of North Carolina’s 2013 Advocacy Day is scheduled for Wednesday, February 20, at the N.C. General Assembly in Raleigh. The two big topics this year are Medicaid expansion and development of the state’s Health Benefit Exchanges under the Affordable Care Act – also known as Obamacare.

Final details are still being arranged, but the general plan is that HNC’s volunteer advocates will gather in the Legislative Auditorium at the General Assembly building on that Wednesday morning, receive a special briefing on issues affecting the bleeding disorders community, and then be encouraged to visit their state representatives and senators with a message that the needs of the bleeding disorders community must not be ignored. If you want Medicaid coverage expanded to cover people who make up to 138 percent of the federal poverty level, if you want a Health Benefit Exchange that is user friendly, and if you want an essential benefits plan that truly covers essential benefits, then this is a gathering you don’t want to miss.

Something else you won’t want to miss is the National Hemophilia Foundation’s 2013 Washington Days gathering, which is scheduled for February 27-March 1 at the Key Bridge Marriott in Arlington, VA. The details are still pending, but be sure to guard the dates.



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2012 Holiday Celebration Rocks! *continued*

over adversity and use his experiences to help others. He inspired all listeners with a new sense of what it means to “give” and a new appreciation for the moral and emotional rewards of helping others.

Crystal Hoernlein, who serves as the volunteer Program Coordinator for HNC’s SOAR group, spoke of the program’s services to women and girls with bleeding disorders. She invited all women and girls with bleeding disorders to take part in SOAR and find emotional and practical support for the challenges in their lives.

Kathy Register received HNC’s Volunteer of the Year Award for her work throughout the transition in Executive Directors from



Kathy Register named 2012 Volunteer of the Year

Sue Cowell to Tom Bennett. Kathy served for four months as the unpaid Interim Executive Director in addition to her ongoing work as HNC’s Treasurer, a post she has held for five years. “In almost thirty years as a non-profit executive I have never encountered a volunteer leader who has shown more skill and dedication than Kathy Register. She is amazing, and HNC is very fortunate to have her steadfast support,” Bennett said.

Santa and Mrs. Claus arrived in plenty of time to distribute gifts to all the children. Each child had a special opportunity to share his or her wish list with the jolly old fellow. We want to thank the Crotts family for all that they do to make this event a time of joy and wonder for the kids.

Every family received a holiday goody bag, but that could be saved for later because the buffet lunch assured that no one left hungry.

After the celebration, those families who wanted to do so had an opportunity to drive through the Carolina Christmas Light Show at Carolina Motor Speedway. This is one of the largest light shows in the country, and the display is said to include more than 3,000,000 lights.

Hemophilia of North Carolina is very grateful to the following sponsors for their support of the Holiday Celebration: Gold Sponsors – Accredo, CSL Behring and Novo Nordisk, and Silver Sponsors – Bayer HealthCare, Hemophilia Preferred Care, Drugco Health, MedPro Rx, Biogen Idec Hemophilia, Specialty Therapeutic Care, Grifols and Walgreens Hemophilia Services.

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Hemophilia of North Carolina is grateful to the following sponsors for their ongoing support of the bleeding disorders community, and for their generous contribution, which made it possible for us to host this event at no cost to HNC member families.

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NC Nominee Takes 2nd Place in National Championship

Jacob Hoernlein, age 9, from Charlotte and Parker Hamby, age 15, also from North Carolina represented Hemophilia of North Carolina in CSL Behring's 11th annual Gettin' in the Game Junior National Championship (JNC) on September 22, 2012 in Dallas, TX. This year, 93 youngsters from across the country competed in either golf or baseball. The JNC encourages kids with bleeding disorders to stay physically active, learn more about their condition and regularly connect with treatment providers to effectively manage

their health. Accomplished Gettin' in the Game athletes, who themselves have bleeding disorders, held clinics to teach participants the fundamentals of golf and baseball while providing guidance and support. Jacob and Parker did a fine job representing our chapter – both on and off the course – and we are proud to report that Jacob was awarded 2nd place in the golf competition, scoring a 43 on a par-36 nine-hole course.

Donate Your Vehicle to HNC!



Got a car, truck, boat, motorcycle or RV that you no longer need? You can donate that vehicle to Hemophilia of North Carolina, help the bleeding disorders community and get a tax deduction too! Simply go to the HNC web site www.hemophilia-nc.org, click on the link for "Donate Your Car" at the upper right-hand corner of your screen, and follow a few simple instructions. The vehicle does not have to be in running condition.

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We gratefully acknowledge the following individuals who generously donated to HNC during this past quarter of 2012.

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



Donors

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Maria Rapoza (in honor of the Rivas family)
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All those who donated 29 pints of blood for the Kasey Frye fundraiser

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Unión Latina de Hemofilia



Hemophilia Latin Union

No olvidaremos el 2012.

El 2012 ha terminado, y damos la bienvenida con alegría al nuevo año, el cual viene cargado de nuevas esperanzas y oportunidades. Una vez más las personas que viven con algún desorden sanguíneo, y sus familias, han tenido la oportunidad de aprender nuevos conocimientos y de compartir experiencias personales de mucho valor para todos aquellos que han asistido a las reuniones del Grupo de la Unión Latina de HNC. Nuestro programa tiene el firme propósito de entrenar a nuestros miembros para que adquieran nuevas habilidades y conocimientos acerca de los recursos disponibles que les ayuden a enfrentarse de la menor forma ante situaciones difíciles relacionadas con la salud, finanzas y asuntos personales que en ocasiones pudieran llegar a complicarse debido al desorden sanguíneo que padecen. No importa en que área de Carolina del Norte vivan las familias, ni el país del cual son originarios; lo que en realidad es de importancia para nuestros miembros, es el interés que todos ellos comparten: El alcanzar y mantener un estilo saludable de vida.

A través del año los miembros del grupo no dejan de expresar lo significativo que es para ellos el formar parte de La Unión Latina, el cual lo ven como parte de su familia. Es dentro de la familia, de la cual formamos parte, donde encontramos apoyo, consejos, respeto y aceptación, todos estos son algunos de los valores que nuestras familias latinas han encontrado en este exitoso programa de la Asociación de Hemofilia de Carolina del Norte.

El Grupo de la Unión Latina no puede cerrar el 2012 sin reconocer a todos aquellos que han aceptado a nuestra comunidad, haciéndonos sentir como en casa: Rita, Charlene, Karla, Tom y Brey.

¡Les deseamos un feliz y saludable 2013!

!Gracias por hacerlo posible! **Baxter** Thanks for making it possible!

We will not forget 2012 .

The 2012 is already gone, and we gratefully say “welcome” to the new one which comes all loaded with new hopes and opportunities. Once again the Latino patients with bleeding disorders and their families have had the opportunity to gain new knowledge and to share valued personal experiences when attending to the reunions of the HNC-Latin Union meetings. Our program has the firm purpose of providing our members with the right set of skills and resources that will help them to better deal with health, financial and personal issues caused by the complexity of their bleeding disorders. It does not matter at all what area of North Carolina each family lives in or which country they have come from; what really matters is that all of our members are bonded by the same interest, to reach and maintain a healthy life style.

Throughout the year members of the group kept expressing how lucky they are to be part of the Latin Union, which is viewed by them as an extended family. It is within your family where you find support, guidance, respect and acceptance, and all of these are values our Latino families have found in this very successful program of hemophilia of North Carolina.

The Latin Union cannot close the 2012 year without giving recognition to all those who have embrace our community and have made us feel at home: Rita, Charlene, Karla, Tom and Brey.

We wish you a happy and healthy 2013!

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-

Aún estamos trabajando en las fechas y lugares para las reuniones del 2013. Llámanos o envíanos un email con tus sugerencias.
!Gracias!

Para mas información llama a Guillermo Sánchez:

1-855-462-5286

O escribenos un email.

union.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.



Aviso: El siguiente es un artículo con fines educativos y de información, antes de tomar cualquier decisión de tratamiento consulte con su médico del Centro de Atención a la Hemofilia (HTC, por sus siglas en inglés)

Ejercicio, Deporte y Fisioterapia.

La mayoría de las personas con algún desorden sanguíneo sufren problemas de sangrado muscular esquelético, como hemartrosis (sangrado de las articulaciones) y hematomas (sangrado de los músculos). Las articulaciones comprometidas con mayor frecuencia son las caderas, hombros y muñecas. Las hemorragias musculares pueden presentarse en cualquier músculo. El músculo de la pantorrilla es un sitio también común de sangrados al igual que cuádriceps y bíceps (músculos del antebrazo). Estas hemorragias producen dolor, inflamación y limitación del movimiento, pueden conducir a atrofia muscular y cambios en la posición normal de la articulación afectada si no se recibe el tratamiento adecuado. Una vez que se controla la hemorragia es necesario recuperar la función normal articular o del músculo, y una rutina de ejercicios apropiados es una herramienta indispensable.

Fisioterapia

La fisioterapia tiene como objetivo mantener y aumentar la movilidad de las articulaciones, mejorar la potencia muscular, intentando recuperar la función normal de la articulación o región afectada. En el tratamiento de fisioterapia se consideran dos fases: La parte preventiva, dirigida a personas con riesgo de desarrollar o repetir una hemorragia. Si una persona mejora su condición física general, es decir la fuerza y flexibilidad de los músculos, estos darán mejor apoyo a las articulaciones y serán menos probables las hemorragias. La segunda fase es el tratamiento que se realice cuando se presenta un sangrado en una articulación, ya sea por primera vez o después de sangrados anteriores.

Deportes

Son ejercicios que se realizan en grupo o en forma individual y cuyo objetivo es divertir, producir satisfacción y crear sentimientos de confianza y mejorar el proceso de sociabilización. No se sugiere que las actividades deportivas se han consideradas de competición para las personas con desordenes sanguíneos: el éxito y el rendimiento en los deportes se basa en las condiciones físicas, habilidades, tipo de desorden sanguíneo y tratamiento que cada una de las personas este experimentando al momento de la actividad deportiva. Antes de comenzar cualquier actividad deportiva debe de hablarse con el médico especialista en desordenes sanguíneos.

Ejercicios

Los ejercicios son actividades programadas, repetitivas y progresivas que requieren orientación y ayuda por parte de un profesional. Los ejercicios aumentan la potencia del músculo, manteniendo o aumentando la movilidad y disminuyendo la deformidad. Los miembros inferiores y el tronco se pueden beneficiar al practicar estos ejercicios, teniendo en cuenta que deben realizarse para ambos lados del cuerpo.

Recuerda: !Mente Sana en Cuerpo Sano!

Consejo Rápido

! Aliméntate Sanamente!

Intenta estas ideas día con día y pronto te sentirás mejor física y emocionalmente:

- a) Come porciones adecuadas y evita comer durante todo el día y sin horarios.
- b) Usa menos grasa al cocinar y limita el consumo de alimentos altos en grasa.
- c) Consume alimentos ricos en fibra y granos.
- d) Cocina con menos sal.
- e) Come frutas y verduras de todos los colores
- f) Limita el consumo de alcohol y refrescos.

Intenta seguir estos consejos poco a poco:

Toma tiempo lograr metas que perduran.

2012 Hemophilia Walk *continued*



If this is Robin, where is Batman?

sustain the frolic, and Gerald Owens of WRAL-TV (a new emcee this year) presided over the event with grace, authority and good humor.

Walk activities included: a photo booth provided by MedPro Rx, face painting at the HPC tent, getting a massage from the Miller-Motte College students, sign making for Walk teams and honorees at the Baxter booth, visiting the Grifols' Mad Scientist and taking a slap shot at the booth set up by the Carolina Hurricanes.

Walk Manager Nicole Bailey's roots as an NC State alumna showed clearly in the presence of the NC State cheerleaders, who were joined at the Walk by the NCSU mascots Mr. and

Ms. Wuf. The cheerleaders and the mascots were great fun and interacted beautifully with the walkers. In addition, NC State donated four tickets to the NC State-Boston College football game, plus an autographed football from the coach.

Everyone seemed to enjoy the abundant and tasty food that was provided. These items included breakfast muffins from Another Broken Egg and bagels from Bruegger's. Starbucks was also present to serve coffee and hot chocolate. For lunch, Jason's Deli offered bagged meals with all the fixings, and a Jason's Deli representative was on hand to help serve the meal.

The volunteers did a great job on Walk day. The volunteer coordinator, Hayden Dawes, did outstanding work and got everything done. He was one of the many volunteers from the NC State School of Social Work. The event also drew volunteers from a local high school key club. Matt Igleman led the vital and challenging parking effort and handled it beautifully.

Charlene Cowell headed up registration and did a great job of seeing that registration and the receipt of donations went smoothly. Speaking of donations, it's high time to recognize the outstanding work done by our Award Winners, our Top Teams and Top Fundraisers.

Award Winners

The Hospital Cup went to the UNC Hemophilia Treatment Center. The King Droplet Award was taken home by Mark Davis, Queen Droplet to Erin Otey, Junior Droplet to Jaden Cook, and the Individual Grand Prize (an Ipad) went to Lawanda McDowell.

Top Teams

- (01) Biogen Idec Hemophilia - \$16,943
- (02) Jaden's Jewels - \$7,823
- (03) Clot Hoppers - \$4,730
- (04) M.L.D. - \$3,625
- (05) Wonderfully Made - \$3,074
- (06) GRIFOLS - \$2,410
- (07) Team Hooker - \$2,330
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- (11) Accredo's Hemophilia Health Services - \$1,482
- (12) Team Hulk Smash - \$1,425
- (13) The Woodge Factor - \$1,315
- (14) Team for Terry - \$1,245
- (15) SOAR - \$990
- (16) Team Andrews - \$871
- (17) Wake Walkers - \$860
- (18) Rob Co's Finest - \$825
- (19) Miles for Andrew - \$785
- (20) Cayton's Clotters - \$680

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2012 Hemophilia Walk *continued*

- (05) Tyronna Hooker - \$2,250
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- (07) Ashley (Mark & Landon) Davis - \$1,300
- (08) Charlene Cowell - \$1,095
- (09) Jeff Harper - \$900
- (10) Maxine Locklear - \$825
- (11) Julia Fielding - \$700
- (12) Anita Smith - \$625
- (13) Gillian Schultz - \$625
- (14) Sharon Sebolt - \$560
- (15) JoAnn Hotta - \$500
- (16) Marisa Labanca \$490
- (17) Karl Schultz - \$425
- (18) Shannon Elderdice - \$400
- (19) Julie Baker \$400
- (20) Helen Blaquiere - \$375

Jordana Zeger, the National Hemophilia Foundation's Chief Operating Officer, brought greetings from NHF. She noted that the Hemophilia of North Carolina Walk is the third largest in the country, and that the numerous walks across the country earn more than \$1 million annually.

We gratefully acknowledge the support of our many corporate sponsors: National Presenting Sponsor – Baxter; Local Presenting Sponsor – Grifols; Gold Sponsors – Biogen Idec, CVS Caremark, Drugco Health, HPC Intl., MedPro Rx, Novo Nordisk, Walgreens



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A lovely butterfly joins the walk

Walk Event Manager Nicole Bailey "made the ask" for funding from our supporters and did so with great success. She recruited and organized a large cohort



Two of Terry's Trailblazers

of volunteers, handled hundreds of details and made sure that everything was in place and ran smoothly. Thanks to her excellent work and the support of many others, the 2012 NC Hemophilia Walk became a record-breaking success. Though we haven't got enough space to thank every single volunteer by name, we want each of you to know that you have our deepest gratitude for your work on behalf of the bleeding disorders community. At the end of the day what counts is that our success with the Walk will help people with bleeding disorders across North Carolina and the whole nation.

Our next Hemophilia Walk is scheduled for Saturday, October 19, 2013, again at beautiful Lake Crabtree County Park. Mark that date and plan to be there with your own mammoth team of walkers!

After The Election: A Consumer's Guide To The Health Law

By Mary Agnes Carey and Jenny Gold

Now that President Barack Obama has won a second term, the Affordable Care Act is back on a fast track. Some analysts argue that there could be modifications to reduce federal spending as part of a broader deficit deal; for now, this is just speculation. What is clear is that the law will have sweeping ramifications for consumers, state officials, employers and health care providers, including hospitals and doctors.

While some of the key features don't kick in until 2014, the law has already altered the health care industry and established a number of consumer benefits. Here's a primer on parts of the law already up and running, what's to come and ways that provisions could still be altered.

I don't have health insurance. Under the law, will I have to buy it and what happens if I don't?

Today, you are not required to have health insurance. But beginning in 2014, most people will have to have it or pay a fine. For individuals, the penalty would start at \$95 a year, or up to 1 percent of income, whichever is greater, and rise to \$695, or 2.5 percent of income, by 2016. For families the penalty would be \$2,085 or 2.5 percent of household income, whichever is greater. The requirement to have coverage can be waived for several reasons, including financial hardship or religious beliefs.

Millions of additional people will qualify for Medicaid or federal subsidies to buy insurance under the law. While some states, including

most recently Alabama, Wyoming and Montana, have passed laws to block the requirement to carry health insurance, those provisions do not override federal law.

I get my health coverage at work and want to keep my current plan. Will I be able to do that? How will my plan be affected by the health law?

If you get insurance through your job, it is likely to stay that way. But, just as before the law was passed, your employer is not obligated to keep the current plan and may change premiums, deductibles, co-pays and network coverage.

You may have seen some law-related changes already. For example, most plans now ban lifetime coverage limits and include a guarantee that an adult child up to age 26 who can't get health insurance at a job can stay on her parents' health plan.

What other parts of the law are now in place?

You are likely to be eligible for preventive services with no out-of-pocket costs, such as breast cancer screenings and cholesterol tests. Health plans can't cancel your coverage once you get sick – a practice known as “rescission” – unless you committed fraud when you applied for coverage. Children with pre-existing conditions cannot be denied coverage. This will apply to adults in 2014. Insurers will have to provide rebates to consumers if they spend less than 80 to 85 percent of premium dollars on medical care.

Some existing plans, if they haven't changed significantly since passage of the law, do not have to abide by certain parts of the law. For example, these “grandfathered” plans can still charge beneficiaries part of the cost of preventive services. If you're currently in one of these plans, and your employer makes significant changes, such as raising your out-of-pocket costs, the plan would then have to abide by all aspects of the health law.

I want health insurance but I can't afford it. What will I do?

Depending on your income, you might be eligible for Medicaid. Currently, in most states nonelderly adults without minor children don't qualify for Medicaid. But beginning in 2014, the federal government is offering to pay the cost of an expansion in the programs so that anyone with an income at or lower than 133 percent of the federal poverty level, (which based on current guidelines would be \$14,856 for an individual or \$30,656 for a family of four) will be eligible for Medicaid.

The Supreme Court, however, ruled in June that states cannot be forced to make that change. Republican governors in several states have said that they will refuse the expansion, though that may change now that Obama has been re-elected.

What if I make too much money for Medicaid but still can't afford to buy insurance?

You might be eligible for government subsidies to help you pay for private insurance sold in the state-based insurance marketplaces,

Continued on page 13

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After the Election *continued*

called exchanges, slated to begin operation in 2014. Exchanges will sell insurance plans to individuals and small businesses. These premium subsidies will be available for individuals and families with incomes between 133 percent and 400 percent of the poverty level, or \$14,856 to \$44,680 for individuals and \$30,656 to \$92,200 for a family of four (based on current guidelines).

Will it be easier for me to get coverage even if I have health problems?

Insurers will be barred from rejecting applicants based on health status once the exchanges are operating in 2014.

I own a small business. Will I have to buy health insurance for my workers?

No employer is required to provide insurance. But starting in 2014, businesses with 50 or more employees that don't provide health care coverage and have at least one full-time worker who receives subsidized coverage in the health insurance exchange will have to pay a fee of \$2,000 per full-time employee. The firm's first 30 workers would be excluded from the fee. However, firms with 50 or fewer people won't face any penalties. In addition, if you own a small business, the health law offers a tax credit to help cover the cost. Employers with 25 or fewer full-time workers who earn an average yearly salary of

\$50,000 or less today can get tax credits of up to 35 percent of the cost of premiums. The credit increases to 50 percent in 2014.

I'm over 65. How does the legislation affect seniors?

The law is narrowing a gap in the Medicare Part D prescription drug plan known as the "donut hole." That's when seniors who have paid a certain initial amount in prescription costs have to pay for all of their drug costs until they spend a total of \$4,700 for the year. Then the plan coverage begins again.

That coverage gap will be closed entirely by 2020. Seniors will still be responsible for 25 percent of their prescription drug costs. So far, 5.6 million seniors have saved \$4.8 billion on prescription drugs, according to the Department of Health and Human Services.

The law also expanded Medicare's coverage of preventive services, such as screenings for colon, prostate and breast cancer, which are now free to beneficiaries. Medicare will also pay for an annual wellness visit to the doctor. HHS reports that during the first nine months of 2012, more than 20.7 million Medicare beneficiaries have received preventive services at no cost.

The health law reduced the federal government's payments to Medicare Advantage plans, run by private insurers as an alternative

Continued on page 14



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After the Election *continued*

to the traditional Medicare. Medicare Advantage costs more per beneficiary than traditional Medicare. Critics of those payment cuts say that could mean the private plans may not offer many extra benefits, such as free eyeglasses, hearing aids and gym memberships, that they now provide.

Will I have to pay more for my health care because of the law?

No one knows for sure. Even supporters of the law acknowledge its steps to control health costs, such as incentives to coordinate care better, may take a while to show significant savings. Opponents say the law’s additional coverage requirements will make health insurance more expensive for individuals and for the government. That said, there are some new taxes and fees. For example, starting in 2013, individuals with earnings above \$200,000 and married couples making more than \$250,000 will pay a Medicare payroll tax of 2.35 percent, up from the current 1.45 percent, on income over those thresholds. In addition, higher-income people will face a 3.8 percent tax on unearned income, such as dividends and interest.

Starting in 2018, the law also will impose a 40 percent excise tax on the portion of most employer-sponsored health coverage (excluding dental and vision) that exceeds \$10,200 a year and \$27,500 for

families. The tax has been dubbed a “Cadillac” tax because it hits the most generous plans.

In addition, the law also imposes taxes and fees on several major health industries. Beginning in 2013, medical device manufacturers and importers must pay a 2.3 percent tax on the sale of any taxable medical device to raise \$29 billion over 10 years. An annual fee for health insurers is expected to raise more than \$100 billion over 10 years, while a fee for brand name drugs will bring in another \$34 billion. Those fees will likely be passed onto consumers in the form of higher premiums.

Has the law hit some bumps in the road?

Yes. For example, the law created high-risk insurance pools to help people purchase health insurance. But enrollment in the pools has been less than expected. As of Aug. 31, 86,072 people had signed up for the high-risk pools, but the program, which began in June 2010, was initially expected to enroll between 200,000 and 400,000 people. The cost and the requirements have been difficult for some to meet.

Applicants must be uninsured for six months because of a pre-existing medical condition before they can join a pool. And because participants are sicker than the general population, the premiums are higher.

Continued on page 15

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After the Election *continued*

Enrollment has increased since the summer, after the premiums were lowered in some states by as much as 40 percent and some states stepped up advertising.

A long-term care provision of the law is dead for now. The Community Living Assistance Services and Supports program (CLASS Act) was designed for people to buy federally guaranteed insurance that would have helped consumers eventually cover some long-term care costs. But last fall, federal officials effectively suspended the program even before it was to begin, saying they could not find a way to make it work financially.

Are there more changes ahead for the law?

Some observers think there could be pressure in Congress to make some changes to the law as a larger package to reduce the deficit. Among those options is scaling back the subsidies that help low-income Americans buy health insurance coverage. The amount of the subsidies, and possibly the Medicaid expansion as well, could be reduced.

It's also possible that some of the taxes on the health care industry, which help pay for the new benefits in the health law, could be rolled back. For example, legislation to repeal the tax on medical device

manufacturers passed the House with support from 37 Democrats (it is not expected to receive Senate consideration this year). Nine House Democrats are co-sponsoring legislation to repeal the law's annual fee on health insurers.

Meanwhile, the Independent Payment Advisory Board (IPAB), one of the most contentious provisions of the health law, is also under continued attack by lawmakers. IPAB is a 15-member panel charged with making recommendations to reduce Medicare spending if the amount the government spends grows beyond a target rate. If Congress chooses not to accept the recommendations, lawmakers must pass alternative cuts of the same size.

Some Republicans argue that the board amounts to health care rationing and some Democrats have said that they think the panel would transfer power that belongs on Capitol Hill to the executive branch. In March, the House voted to repeal IPAB.

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The Case for Medicaid Expansion

The author of the following two items is Leonard Poe, who serves as Vice President of HNC and Chairman of our Advocacy Committee. He practices law in Western North Carolina. National sources estimate that one-third of the bleeding disorders community is on Medicaid. -TVB

The Affordable Care Act (ACA) sought to expand Medicaid to cover all people living in poverty. Currently Medicaid, with some exceptions, only covers the impoverished young and elderly. The Supreme Court has ruled that each state has the option to reject the additional funding and the expansion of Medicaid. Now our state must decide: should we expand Medicaid to include all the poor, regardless of age?

Maladies and chronic illnesses do not end at age 18, nor begin at age 65. Surely our state would not let its most vulnerable citizens wither and perish simply because they are poor. Our current system, by suspending health care coverage at age 18, forces our young people with chronic illnesses to suffer and deteriorate until they can qualify for social security under stringent disability standards. Our current system ruins young lives and costs us

productive citizens. Expanding Medicaid is the proper course for the state.

Yet budgetary concerns deter certain of our elected officials from embracing what they know is the right thing to do. Those concerns are born of fear more than fact. The federal government is offering to fully pay for that expansion for three years, and to pay 90% of the costs that the state incurs thereafter. The Congressional Budget Office estimates that our state's 10% participation will only cause a 2.6% increase in the Medicaid expenditures we are already committed to make. That finding is confirmed by independent studies from the Urban Institute and Lewin Group. Far from a budget-busting boondoggle, that moderate increase in expenditures is no impediment to a committed legislature.

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Medicaid Expansion *continued*

Our reluctant representatives should be far more concerned about the opportunity costs of NOT expanding Medicaid. When poor people take ill, they show up in emergency rooms and clinics anyway. Doctors and hospitals have legal and ethical duties to treat them. The unpaid costs of their care are thus borne by the people who treat them, or passed on in higher prices for the rest of us. This is unfair and unnecessary. The federal government is offering to cover these costs for us. In the short term the federal dollars that the Medicaid expansion brings to our state will create good

jobs and income for our citizens right when our economy needs just such a boost. And even when the state has to shoulder a small part of the costs, attracting nine federal dollars for each state dollar spent is an economic incentive we can ill afford to forego.

For all these reasons, right-minded state legislators should find ways to take the federal money and expand Medicaid for the health of its poor citizens, the benefit of its medical practitioners, and the expansion of our state economy.

Health Care in the Absence of Medicaid Expansion

Medicaid is the vehicle through which our federal government wants to fund health care for the poor. If our state chooses to forego this federal/state partnership, we must consider alternatives because poor people will still need health care. Our current system sends poor people to emergency rooms and walk-in clinics without any ability to pay for the services they need. Hospitals and doctors have a legal and ethical obligation to

treat them anyway. We force our medical providers to absorb the unpaid costs of poor people's health care, or to pass those costs on to the rest of us as higher prices. That is bad policy.

Much better policy would be to find another mechanism to pay for the health care costs incurred by the poor. One way is to use

Continued on page 18



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Absence of Medicaid Expansion *continued*

private insurance. The problem is premium costs. The Affordable Care Act provides tax credits and subsidies to help persons with incomes between 100 and 400 percent of the poverty level afford the premiums they will have to pay. We need to help and encourage people living in poverty to procure health insurance through the new health benefit exchanges (HBEs). Because the ACA anticipated that everyone below the poverty level would be on Medicaid, there is no help for the poor with their premiums. This is a newly created gap in the ACA that obviously needs to be fixed with a simple amendment to the Act. Simultaneously, states should use their regulatory power over insurance companies selling policies through the HBEs to control costs to our impoverished citizens.

Another approach is to use existing state and federal high-risk pools to subsidize the health care costs of the poor. These

pools are supposed to become obsolete when the health benefit exchanges and Medicaid expansion take effect on January 2014. Now that the Medicaid expansion is not going to be universal, they may have a new purpose. Income-based, sliding-scale premiums can be implemented to allow fair share participation and contribution by those of meager means. The pools would be able to use Medicaid's approach to cost savings and economies of scale without Medicaid's all-or-nothing approach to coverage. This option would require more comprehensive amendments to the state and federal high-risk pool statutes, but would keep the problem of health care costs for the poor in the public sector.

A choice must be made. It is irresponsible to leave the most vulnerable of our citizens without realistic health care options while the Affordable Care Act is implemented for the rest of us.

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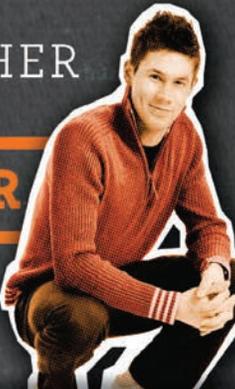
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Type _____ (VIII, IX, VWD, etc.)

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