“A Celebration of Caregivers” at the 2013 HNC Holiday Celebration

On December 7th, Hemophilia of North Carolina’s community members joined together for the 2013 Holiday Celebration in Morrisville!

The adults had time to relax and visit with friends before the presentations began. The kids were busy making fun crafts including magnetic holiday characters for their refrigerators and colorful candy cane holders! A slideshow montage was then shown of pictures from all of the HNC events throughout the year while holiday-themed music played in the background.

After attendees had an opportunity to visit the sponsor exhibits, it was time to start the presentations. Charlene Cowell, HNC’s Executive Director, kicked off the afternoon with a warm greeting to the crowd. Gillian Schultz, HNC’s HOPE Program Coordinator, shared a glimpse of the HOPE program and plans for 2014.

This year, we celebrated all of those who support their loved ones. Who better to speak on this than fellow HNC members? We heard from four people who truly know what it means to give and receive.

2013 Volunteers of the Year

As a non-profit organization serving a sizeable state with a small staff, volunteers have been the lifeblood of Hemophilia of North Carolina. For over 40 years, this organization has thrived because of volunteer support and members with diverse talents. In 2007, in an effort to recognize HNC’s hardest working members, we created the Volunteer of the Year award.

We are fortunate to have such a caring and supportive community of friends and volunteers. Our volunteers have been instrumental in developing HNC’s programs and services. These programs have benefited many of our community members and continue to make an impact.

Gillian Schultz and Crystal Hoernlein each took home an award for being HNC’s 2013 Volunteer of the Year. Both of these passionate and energetic women have done so much for Hemophilia of North Carolina over the past year.

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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.

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.

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557
(919) 319-0014
(919) 319-0016 (fax)

National Hemophilia Foundation
(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America
(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC
(919) 554-3272 (Collect)
www.healthcharities.org

About This Publication

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

An electronic version may be found on the HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

We maintain a membership mailing list. However, we never release any personal information without your permission.

Hemophilia of North Carolina does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

Hemophilia Treatment Centers

East Carolina University
Brody School of Medicine
600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

University of North Carolina
At Chapel Hill
School of Medicine
Campus Box 7016
Physician Office Building
170 Manning Drive
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

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

Additional Medical Resources

Carolina's 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

Novant Health 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.hemophilafed.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)
1-800-488-2688
www.cott1.org

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

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

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

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

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.
Happy New Year! I hope that everyone is excited about what 2014 may bring. As I settle into my new role as Hemophilia of North Carolina’s Executive Director I find myself energized and inspired about the future possibilities.

Some members may remember me from events as early as 2007, when I began volunteering for Hemophilia of North Carolina. Immediately I felt connected to this community and was welcomed with open arms. Being the daughter of the then-Executive Director, Sue Cowell, I looked forward to my weekends filled with HNC activities. I know most teens wouldn’t include working along side their mom on the “Top 5 Favorite Things” list but this was #1 for me, thanks to members like you.

Seven rewarding years later, I am honored to be your Executive Director. I’ve grown with this organization and its members, listened to the needs of this community and built heartfelt relationships with many of you. I look forward to creating new memories in the years to come.

Some of my goals for the next few years include: evaluating and enhancing our already-existing programs and services; strengthening our relationships with hematology centers across the state; and working with our members to continue meeting the needs of our community. Over the years, we have worked hard to make sure the programs and services offered are comprehensive and impactful. I believe that as an organization formed by members, for the members, it is important to plan our future based on your feedback and participation. Through discussions with members, forming committees, and collaborating with the many clinicians in NC, HNC will continue to build on our foundation’s vision. By working together, HNC will continue as a vital resource for anyone affected by a bleeding disorder. I sincerely thank everyone who has made Hemophilia of North Carolina what it is today.

Since one of my goals is to get to know each and every one of you better over the coming year, I would like to start by sharing a little bit about me…

An interesting fact about me…
In retirement, I envision myself on a huge farm surrounded by rescue animals. My passion for animals is as close to my heart as HNC.

A quote that inspires me…
“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” — Margaret Mead

Warmest Wishes in 2014,
Charlene

Charlene Cowell, Executive Director
HNC’s Walkers Surpass the $100,000 Goal!

The skies were gray but smiles were bright at the 6th Annual HNC Hemophilia Walk! And for the second year in a row, HNC supporters exceeded expectations and raised $103,728!

In spite of the early morning rain and the gloomy forecast, many hundreds of hearty souls turned out for a splendid event. The rain stopped for good as the registration desk opened at 9am. As walkers arrived they fortified themselves with Starbucks coffee and hot cocoa from Panera, then moved on to yummy fruit from Whole Foods and bagels provided in part by a gift from an anonymous donor. Not far away our four-legged walkers found bags of Pet Mania doggie treats awaiting them.

Throughout the morning we were entertained by the Durham Bulls mascot, Wool E. Bull, and by SpongeBob SquarePants. The talented face painter at the HPC booth was always busy with a line of eager kids. There was also the fun Carolina Hurricanes Slap Shot for those who wanted to test their hockey goal shooting talents. The always popular photo booth from MidAtlantic Photo was back this year, thanks to MedPro Rx. And Kevin McVerry of Performance DJ kept the tunes coming.

Right on schedule, Laura Meyers, HNC’s 2013 Walk Manager, welcomed the group and introduced HNC president Steve Peretti. Steve then presented HNC’s new Executive Director Charlene Cowell, who introduced our Master of Ceremonies, Angelica Alvarez from WTVD TV-11 Raleigh-Durham.

Jecoreiography, the amazing and energetic dance group who enthralled the crowd at last year’s Walk, returned to repeat their magic this year. They did not disappoint. We hope they will return next year too.

Angelica called up all the kids who came to the Walk dressed in their Halloween finest. After much consideration, the judges ruled an all-way tie, and each costumed contestant was awarded a candy bag prize.

Steve then introduced our special guest, Mary Ann Ludwig, Vice President for Development at the National Hemophilia Foundation. Mary Ann stressed the importance of broad community participation in fund raising, and thanked everyone for their hard work on this year’s Walk.

Each year several special awards are given in recognition of outstanding effort and success in support of the Walk:

1. The Hospital Cup, awarded to the medical group or hemophilia treatment center team that raised the most funds, went to the UNC TarHealers, with team captain Tracy Griles accepting the trophy.

2. Todd Holder, representing National Presenting Sponsor Baxter International Inc., announced a new award this year in recognition of the Top Fundraising Team (non-industry). That award went to the Clot Hoppers team, with team captain Kathy Register accepting the trophy.

3. Each year HNC presents the Royal Droplet award to a man, woman, and young person in recognition of their individual outstanding effort in support of the Walk. This year’s Droplet King is Jerry Smith of the One Drop team; the Droplet Queen is Kathy Register of the Clot Hoppers; and Leo Sebolt of The Woodge Factor is the Junior Droplet.

Finally it was time to start Walking! Angelica called on Erica Cook, this year’s Walk Chair, to assemble her team and lead the way. Erica gathered with her Jaden’s Jewels and Jaden’s Gents and the 2013 Walk was under way!
As the weary walkers returned they were immediately lured to the Popsicle cart manned by Todd Holder and Brey Curtis from Baxter International Inc. They then moved on to grab a ham, turkey, or veggie bag lunch provided by Jason’s Deli. And there was plenty of cold bottled water provided by Walgreens Bleeding Disorder Services.

We are grateful to all of our sponsors for their generous support of the 2013 Hemophilia Walk. Very special thanks go to our teams and their captains for their super effort to surpass our goal.

**Top 3 Fundraising Teams and Captains**

Biogen Idec Hemophilia - Nikita Lyons Murry
Clot Hoppers - Kathy Register
Jaden’s Jewels/Jaden’s Gents - Erica Cook

**Our Teams and Captains**

Accredo’s Hemophilia Health Services - Diane Mauldin
Bennett’s BioRx Team - Chris & Matt Barnes
Camden Alipour - Camden Alipour
Cayton’s Clotters - Shannon Elderdice
CVS Caremark - Wayne Cook
GRIFOLS - Jeff Bridges
Hemo Hero - Erika Wilson
HemTeam - NHF
HPC Bruise Crew - Nicole Bailey
Hulk Smash - Gillian Schultz
M & M Team - Ruth Vega Marquez
Miles for Andrew - Helen Blaquiere
M. L. D. - Ashley Davis
One Drop - Dawn Smith
Peachtree - Stefanie Balch
Rob Co’s Finest - Tisha Locklear
Sir Clots-A-Not and the False Clots - Reid Coleman
SOAR - Crystal Hoernlein
South Cows - Charlene Cowell
Specialty Therapeutic Care - Jeff Harper
Taylor JAGS - Leroy Taylor
Team Andrews - Scott Andrews
Team Drugco - Tiffany Holland
Team Hooker - Tyronna Hooker
Team Matrix - Peggy Gay
UNC TarHealers - Tracy Griles
vAmpire hAit - Crystal Hoernlein
von WilleWhat!? - Annie Jagger
Wake Walkers - Anita Smith
Wonderfully Made - Erin Otey
The Woodge Factor - Sharon Sebolt

**Walk Sponsors**

**National Sponsors**

**National Presenting Sponsor:** Baxter International Inc.

**Pacesetter Sponsor:** Bayer Healthcare

**Official Sponsors:**

Grifols
Pfizer Hemophilia
Biogen Idec Hemophilia

**Local Sponsors**

**Local Presenting Sponsor:** Grifols

**Gold Sponsors:**

Accredo
Biogen Idec Hemophilia
Drugco Health
HPC International
MedPro Rx
Novo Nordisk

**Silver Sponsors:**

CVS Caremark
Kedrion Biopharma

**Bronze Sponsors:**

Coram
Factor 4 Life
Octapharma

**Specialty Therapeutic Care**

**Kilometer Sponsors:**

AHF, Inc.
Hemophilia First

**Media Sponsor:**

ABC11 WTVD

**Local Walk Partner:**

Wake County

**In-Kind Sponsors:**

Carolina Hurricanes
Instant Imprints
Jason’s Deli
Pet Mania
Starbucks
Walgreens Bleeding Disorder Services
Whole Foods Market

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**Save the Date for HNC’s Walk 2014**

**Saturday October 11, 2014**
“A Celebration of Caregivers”

support. We thank Parker Hamby, Matt Igelman, Claire Redfield, and Dawn Smith for sharing their stories with us. Sally Wright, UNC HTC Clinical Program Manager, closed out this portion of the program with a very funny recap of HNC over the year and her thoughts and experience on supporting each other.

Many thanks to all our creative volunteers who helped make the event festive and fun. Centerpieces were custom made by Gina Raymond-Duncan and Nicole Bailey. As part of the centerpieces, attendees were encouraged to write inspirational messages or names of those they wanted to recognize for supporting them on snowflake paper ornaments. These unique ornaments were designed and handmade by Tat’ya Shchetinina. The personalized messages are in safe keeping and will be displayed on a tree at our 2014 Holiday Celebration.

Taking time out from his busy schedule, Santa stopped by for a visit! Each child took time to share his or her wish lists with Santa and everyone received a special holiday gift. Our special thanks to Terry Crotts for always making this a memorable moment for the children! This was Terry’s seventh appearance as Santa, and we are always grateful to him and his family for all their support with the holiday celebration over the years.

We also made our annual Volunteer of the Year presentation at the event. Awards were given to Crystal Hoernlein and Gillian Schultz for a year of extraordinary volunteer service to the community with the HNC SOAR and HOPE Programs.

As the kids left with arms full of goodies, each family came away with a bag of sweet treats! Our thanks to all of the companies and individuals who donated items for the chocolate gifts and raffle prizes.

Charlene ended the evening with a heartfelt thank you and happy holiday wishes to all!

A Few Ornament Messages

My husband inspires me
I’d like to thank my parents for giving me my medicine and teaching me how to put it in myself
I am thankful and grateful for the love of my life!
The perseverance of the families affected has always inspired me
My wife for the vigilant care she gives the family
My daughter because she has the courage to get up every day and her positive outlook despite her health issues
The NHF 65th Annual Meeting

With more than a dozen HNC members in attendance at the National Hemophilia Foundation (NHF) Annual Meeting in Anaheim, CA, the state was well represented! October 3-5 was the NHF’s 65th Annual Meeting with attendance nearing 3,000 people. With a broad range of educational sessions and various opportunities for networking, this was another successful national conference. Participation in national conferences allows us to hear more about current and future education and research. As a special treat, Charlene Cowell and Wayne Cook of CVS Caremark had the chance to meet Alex Borstein, voice of Lois Griffin from Fox’s Family Guy.

Alex grew up in a family with hemophilia and is the NHF’s new spokesperson for genetic testing.

Hemophilia of North Carolina is fortunate to have funding available to attend national conferences and we encourage families and individuals to consider joining us at future meetings. Please visit the HNC website (under Programs & Services) for more information on conference scholarships.

Baxter's vision is a life without bleeds

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

Over the years, Baxter has been the leader in providing support and resources for the community. Today, we are continuing to improve treatment for bleeding disorders. We have seven ongoing clinical trials, including those targeting hemophilia A, hemophilia B, inhibitors, and von Willebrand Disease.

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

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

Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.
Blood Brotherhood Winterfest

There was no snow on the ground, but it was still a cold December night for the HNC Blood Brotherhood Winterfest in Concord. Of course we weren’t the only ones with the idea of staying warm at the Concord Mills mall right before the holiday! Once they found a parking spot, Blood Brothers and their loved ones ventured into the Dave & Busters for a night filled with friends and excitement. Between shooting pool and playing arcade games, we all had a smile on our faces when the night was over!

We’ll have at least five more Blood Brotherhood events coming up in 2014 and hope that you’ll join us:

- February 8 – Chapel Hill
- April 12 – Morrisville
- May 3 – at the HNC Annual Meeting (location TBD)
- July 19 – Asheville
- September 13-15 – Kure Beach*

* The September gathering is our annual retreat. Space will be limited and priority will be given to Blood Brothers who have participated in previous events.

HNC’s Blood Brotherhood program is an extension of HFA’s Blood Brotherhood Program. It is designed to provide opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. It’s a chance to connect with others who have been where they are – people who can share their experiences, suggest a coping skill, or just crack a joke and enjoy each other’s company!

Mourning the Loss of HNC’s Past President, Ed Wilson

We at Hemophilia of North Carolina are saddened by the loss of a true champion in our community. Former HNC President Edwin Wilson, 71, died Sunday, November 17, 2013 at his home in Tryon, NC. Throughout his life he dedicated his time, service, and professionalism to the bleeding disorders community. Beyond our community he was a lieutenant colonel in the Civil Air Patrol, and dedicated time to the Boy Scouts, Kiwanis Club, and Tryon Congregational Church of Christ. His passion for advocacy truly inspired many as he carried the mission and values of our organization to a national spotlight. As a community, we mourn Ed’s passing, appreciating all that he taught, gave, and achieved for us.

2013 Volunteers of the Year

Crystal Hoernlein has been coordinating the SOAR Program since late 2012. If you were at our recent Hemophilia Walk you may remember Crystal and her family; they were selling tutus like hotcakes to raise money for the SOAR Program! You also might notice that we have a supplement for women and girls in our newsletter. This was a goal at the last SOAR retreat and under Crystal’s guidance, we’ve now completed our second SOAR supplement to the HNC newsletter.

Gillian Schultz, as the HOPE Program Coordinator, has a passion for supporting families in our community. As a mom of two, Gillian knows the challenges that life can throw at you. Through her letter, which is provided to all new HNC families and available at the Hemophilia Treatment Centers, Gillian shares her story and experiences. You can find this letter on the HNC website under the “HOPE – Young Families” section. In the past year, Gillian has helped HNC to develop materials for new members, the HOPE section on our website, and an improved system for reaching out to new families.

It is a privilege to work with both Gillian and Crystal, who give selflessly of their time and efforts to HNC and its programs to make them impactful. On behalf of the staff and board of directors, we extend our heartfelt thanks to Gillian and Crystal for all of their hard work and continued support.
HOPE News

Things are starting to get busier for the HOPE program. On November 26, HOPE held an educational dinner at Luigi’s in Fayetteville. The dinner, presented by Baxter International Inc., was entitled “Emergencies Happen.” We had a great turn out despite the bad weather. Nancy Roy, MSM, FNP, was the scheduled speaker, but it happened that she had her own emergency that day and could not attend. We were fortunate to have Sue Kovats-Bell, Senior Clinical Specialist with Baxter International Inc., join us with a remote presentation. Sue spoke on how to be prepared for emergencies, how to advocate for proper care in the Emergency Room, and how to prepare for traveling. It was an engaging evening with many personal stories and questions about such a relevant topic for all of us.

At the HNC Holiday Celebration, Gillian Schultz gave a presentation about the HOPE program. Several families expressed interest in future HOPE events.

HOPE is an HNC program designed to support families with children from birth to twelve years old with a bleeding disorder. Open to any member of HNC, programs are specifically planned to meet the unique needs of families with young children dealing with bleeding disorders – to educate and support them so that their children can lead fulfilling lives.

For more information about the HOPE program, please contact Gillian Schultz, Volunteer HOPE Program Coordinator at gillian.schultz@hemophilia-nc.org or Charlene Cowell, Executive Director of HNC at info@hemophilia.nc.org or call the HNC office (800) 990-5557.
This past September, I had the privilege of attending the 13th Annual CSL Behring Junior National Championship in Phoenix, Arizona. The championship is organized by golf pro Perry Parker, who also has Hemophilia. Parker wanted to create an event where kids aged 8-18 who suffer from bleeding disorders could come together and receive training in the fundamentals of golf and baseball along with getting to meet other kids with bleeding disorders.

This year, 116 kids represented 58 bleeding disorder Chapters from across the country.

The weekend’s events started on Friday afternoon with golf and baseball clinics. Being able to learn putting skills from a professional golfer was exactly what I needed to improve my golf score.

Recently, I have taken up golf. This year, I played on my women’s high school golf team, so getting to attend the JNC and receive specialized training couldn’t have come at a better time. My experience at the JNC was amazing. CSL Behring provided us with everything we needed to play a 9-hole tournament including loaner clubs, balls, my own personal caddie and training by a professional golf pro, along with plenty of water and snacks to stay hydrated in the hot Arizona climate.

While kids who signed up for golf were participating in a nine-hole golf tournament, others across town were learning and perfecting their baseball skills.

That weekend, during free time, I was able to meet several teens just like me who suffer from bleeding disorders. We spent time hanging out at the pool and game room; making friends that will last a lifetime.

On Saturday, after the tournament, Parker and other representatives held informative classes and group sessions. I attended a group session where kids could openly ask questions and receive advice from Parker and others in the group.

Saturday evening began with an autograph session with Parker and several professional baseball players. After the autograph session, we had a wonderful dinner. A slide show of the weekend was shown, followed by an awards ceremony. Each participant received a medal for the sport that they participated in.

Words cannot describe how wonderful the entire experience was. I left Phoenix with a better understanding of von Willebrand disease, as well as new skills in golf and several friends.

Thank you Hemophilia of North Carolina for giving me the opportunity to attend this conference and CSL Behring USA for hosting such an awesome event.

Save the Dates!
Be sure to keep your eyes open for the announcement and application details for the 2014 Junior National Championship, which is typically held in September.

HNC has also been selected by CSL Behring to host a Gettin’ in the Game Golf Clinic on Saturday, April 26th. We’re excited to hear that Gettin’ in the Game athlete, Perry Parker, a former PGA touring professional and member of the hemophilia community, will be on hand to lead the clinic. The event will take place in the Charlotte area. More details will follow on our website.
Celebración de Día de los Muertos

El 2 de noviembre, el Latin Union of Hemophilia of North Carolina celebró el Día de los Muertos en la Universidad Wake Forest en Winston-Salem. La presentación para ese día fue sobre la reforma de la ley de salud y cómo afecta a personas con enfermedades relacionadas con hemofilia. Karla Zevallos, Educadora Bilingüe de Salud para Baxter NC, ayudó a todos a entender mejor los cambios en la ley de salud para los cuales debemos prepararnos. Mientras los adultos oían y participaban en una excelente sesión de preguntas y respuestas, los niños disfrutaron una película de aventuras sobre Don Quijote.

Después de una buena comida, todos disfrutaron un precioso día de otoño, mientras caminaban por el campus al Museo de Antropología. Al entrar al museo, los recibió la pintoresca exhibición de Día de los Muertos. El museo, fundado en 1963, es el único en North Carolina dedicado al estudio de las culturas del mundo, y está muy bien puesto. Cuando terminó la visita, los miembros del grupo se despidieron hasta el siguiente evento del Latin Union.

Retiro del Latin Union en 2013

El 7 de diciembre, el Latin Union se reunió de nuevo para su Tercer Retiro Latino Anual. El retiro fue en la celebración de los días festivos de la HNC en Morrisville. ¡Allí recibieron la visita de Santa Claus! Hicieron artesanías de los días festivos y disfrutaron abriendo sus regalos traídos del Polo Norte. Pasaron la noche en el hotel y soñaron todas las cosas divertidas que harían el siguiente día.

Después del desayuno, el grupo del Latin Union pasó el día en la oficina de HNC. Marvin Poole de Baxter International, Inc. dio la primera presentación de la mañana. Aunque era temprano, Marvin supo cómo hacer interesante el tema del Mercado de Salud. Cuando nuestros cerebrose llenaron de información, ¡llegó la hora de llenar el estómago! Sirvieron una deliciosa comida de auténticos platillos mexicanos antes de la segunda y última sesión del día. Karla Zevallos terminó el retiro con una presentación enfocada hacia la identificación de hemorragias, las opciones de tratamiento, y como monitorear el estado de salud.

Durante la porción educativa de los programas, los niños tuvieron la opción de ver películas, hacer artesanías, o entretenerse con juegos de video. Como se puede ver en las fotos, ¡fue un fin de semana muy divertido para todo el mundo!
If SOAR gave an award to the wittiest, Dawn Smith would surely be the recipient. Her smile is infectious, and she always brings an incomparable energy with her. But her positive personality masks what she struggled with most of her life. She was often told “some just have it rough, and you are one of them.”

Dawn began hemorrhaging while pregnant with her twin boys in 2000. She was rushed to the hospital where the bleeding finally stopped. This laid the path toward her diagnosis. She expected to stay in the hospital for eight weeks so the twins could continue to develop. However, a second hemorrhage began later the same night, and an emergency c-section was ordered. All three had blood transfusions.

Approximately six months later Dawn’s levels were tested and she figured out why she had it rough. She found out that she is a symptomatic carrier of severe hemophilia A, and she also has mild von Willebrand disease.

With the demands of caring for boys who had numerous health complications in addition to this thing called hemophilia, she put her health on the back burner. Dawn also loved to travel, but travel plans no longer seemed attainable with her bleeding disorder. Dawn became a member of Hemophilia of North Carolina and SOAR.

Dawn shares how the organization has positively affected her life.

“By being a part of Hemophilia of North Carolina and especially SOAR, I am learning to take better care of myself and seek proper medical advice and treatment from my Hemophilia Treatment Center.

SOAR has helped me to gain the confidence that I can live a productive life, overcoming the challenges that a bleeding disorder presents in the life of a woman. SOAR helped me adjust my compass and get back on the road again. In 2012, my heart went to a little village in Welliso, Ethiopia. Our trip was less than 2 weeks, but it took over a year for my heart to return home.

I no longer allow von Willebrand Disease to control me. SOAR can help you too. Get involved. Make a friend.”

Dawn lives in Johnston County and has been a member of Hemophilia of North Carolina since 2000. She spoke at the 2013 Holiday Celebration and encouraged the community to enjoy the gift of support. She is currently involved with our school nurse campaign and is a gift to the bleeding disorders community.

**Thanks to everyone who purchased a tutu at the 2013 Hemophilia Walk!**

For the past few years SOAR members have lovingly donated their time, talents, and resources to craft handmade tutus that raise funds & awareness for SOAR and for girls and women with bleeding disorders at the Hemophilia Walk. The money raised from tutu sales at this year’s walk will help with expenses related to our current school nurse advocacy and awareness campaign.

This tradition is sure to grow and continue into the 2014 Walk season, so please look for more information in the coming year on how to pre-order tutus for next year’s walk!
It’s no surprise that girls and women with bleeding disorders experience heavy monthly bleeds. Quite often menorrhagia (or heavy menstrual bleeding) becomes the norm for families where women are affected. This “normalization” can delay diagnoses and may contribute to the Center for Disease Control data that shows women experience symptoms for an average of 16 years prior to being diagnosed.

A well-informed school nurse may be one of the first to notice the signs and symptoms of bleeding disorders in teen girls. SOAR is launching a “school nurse” campaign to raise awareness for bleeding disorders among girls and women. We will reach out to school nurses in North Carolina in an effort to educate them on what may indicate a bleeding disorder.

SOAR will provide packets of information to school nurses containing:

- signs and symptoms of bleeding disorders
- contact information for North Carolina’s Hemophilia Treatment Centers
- contact information for Hemophilia of North Carolina
- awareness flyers that may be hung in health rooms or bathrooms
- an invitation to schedule an in-service session for additional information

If you are interested in becoming involved with our school nurse campaign, your help is greatly appreciated. We have volunteer opportunities that range from stuffing envelopes to helping plan in-service sessions. Please look for more information to come or send an email to soar@hemophilia-nc.org to find out how you can help!

Have A Happy, Healthy 2014!

Did you know that exercise can raise the level of von Willebrand factor (vWF)? vWF is released in the blood during moderate to high intensity exercise, and as a result there is more of it flowing in the blood.

Not only does exercise raise factor levels, but people who are physically active tend to live longer and have lower risk for heart disease, stroke, type 2 diabetes, depression, and some cancers. Physical activity can also help with weight control, and may improve academic achievement in students.

Here are some easy ways to work fitness into your schedule:

- Take the stairs rather than the elevator
- Park further from a destination
- Exercise as a family (take a walk at the park, shoot some hoops, or kick the soccer ball around)

Exercise should be fun, frequent, and feasible!

If your New Year’s resolutions involve changes to your diet or exercise regime, make sure you speak with your doctor first.
Upcoming Events

7th Annual “Hearts for Hemophilia” Casino Night at Cardinal Hall, Raleigh, NC
Saturday, January 25, 2014

We hope you will join us this year for HNC’s “Hearts for Hemophilia” Casino Night. Our new venue, Cardinal Hall at the Wake County Shrine Club in Raleigh, and our new caterer, Triangle Catering, will prove to be a favorite for both new and returning guests. Tickets are available on the HNC website and through the HNC office.

NHF Washington Days in Washington, D.C.
Wednesday, February 26 - Friday February 28, 2014
Registration is now open

The NHF’s annual Washington Days empowers individuals in the bleeding disorders community to make an impact on the legislative process. Meet face-to-face with lawmakers and staff who shape national healthcare policy, become more informed on critical issues that affect your continued access to quality care, and learn effective grassroots advocacy techniques. For more information, go to www.hemophilia.org and click on “Advocacy” at the top of the page or call NHF at 1-800-424-2634.

2nd Annual Car, Truck and Bike Show to Support HNC
Saturday, March 1, 2014 at 9:00 am
O’Reilly Auto Parts, 1103 N Bragg Blvd, Spring Lake, NC 28390

A family fundraiser to support HNC! Categories will include Best Domestic, Best Muscle, Best SUV, Best Truck, Best Euro, Best Import, Best 1990 and older, Best Custom (all sizes), Best Cruiser, Best Sport Bike, Best mid size truck, Top 5 Bikes, Top 10 Vehicles. Registration $20, Bike $10, Multi Car (Couple) $25. Search for “2nd Annual Car Truck and Bike Show to support Hemophilia of North Carolina” on Facebook for additional information.

HFA Symposium in Tampa, Florida
Thursday, March 27 – Saturday, March 29, 2014
Registration is now open

HFA’s Symposium is an annual community-centered educational event that draws over 400 patients and their families, 100+ exhibitors, 20+ speakers, and over 50 community volunteers from across the country. HFA awards over 100 travel scholarships to first time attendees each year for families who need financial assistance. Act fast as scholarship opportunities go quickly. This national meeting is a place where community members come together to share information, learn new advancements, and build a network of support. For more information, go to www.hemophiliafed.org and click on “Programs & Services” then “Symposium” or call HFA at 1-800-230-9797.

HNC 10th Annual Charity Golf Tournament at The Preserve at Jordan Lake
Friday, April 25, 2014

Join us for a fun-filled day of golf to support HNC. Our special guest player and golf pro, Perry Parker, will be with us again this year so everyone will have a chance to play “Beat the Pro”! There will also be a dinner, a raffle, and special recognition of the day’s many winners. Look for registration information in March.

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Victory Junction Camp in Randleman, NC
Victory Junction is a year-round camping facility that serves children, ages 6 to 16, with chronic medical conditions or serious illnesses, at no cost to their families. During the summer, Victory Junction offers disease-specific sessions for up to 128 children per session. During the fall, winter and spring, family weekends are offered to up to 32 families per weekend. For more information, go to www.victoryjunction.org or call 336-498-9055.

Spring Family Weekends
November 1, 2013: Begin Accepting Spring Family Weekend Applications
4 weeks before the Session starts: Spring Family Weekend Application Deadline
Friday, March 14 – Sunday, March 16, 2014: I Love the 80’s Weekend
Friday, March 21 – Sunday, March 23, 2014: Luck of the Irish Weekend
Friday, April 25 – Sunday, April 27, 2014: Rock ‘n’ Roll Weekend

Summer Camp
January 1, 2014: Summer Camper Application and Schedule Available
April 1, 2014: Summer Camp Application Deadline

Camp Rainbow at Camp Don-Lee, Arapahoe, NC
Camp Rainbow is a week-long summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Camping experience goals include: building self-confidence and independence, emotional and social development and well being, and learning and sharing support with others who are living with a chronic blood disorder. For more information including 2014 camp dates, please call 252-744-4676.

All of these Summer Camps are absolutely necessary for future generations. Please consider supporting them with donations of money and/or time.

Camp Carefree in Stokesdale, NC
Since 1986, Camp Carefree has provided a free, one-week camping experience for kids with bleeding disorders. Camp Carefree provides the needed freedom to play, learn, and have fun with others who encounter similar difficulties. The program also includes camps for children who live with a sibling who is affected by a bleeding disorder (Sibling Camp) and children (not affected) with a parent affected by a bleeding disorder (Kids Camp). For more information, go to www.campcarefree.org or call 336-427-0966.
June 15 – June 21, 2014: Siblings Camp
July 13 – July 19, 2014: Kids Camp
July 20 – July 26, 2014: Hemophilia and vWD Camp

Medical Alert StrapWrap™
Designed especially for people with bleeding disorders, StrapWrap attracts the attention of emergency personnel while it protects confidential medical information inside. StrapWrap fastens with Velcro so you can use it on a seatbelt, backpack or baby carrier.

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Chris Barnes • 919.749.3196
www.biorx.com 866.442.4679
2013 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2013. We extend a sincere thank you to our supporters, some of whom have contributed several times during this period.

Two of our long-standing and revered members, Monroe Poplin and Ed Wilson, passed away in December. Their service to HNC and to the bleeding disorders community will not be forgotten.

Donors
Richard Atwood • Lucretia Brendler • Rita Brown • Mark and Jo Anne Buckley
Lori Conger • Charlene Cowell • Christine Cowell • Sue and Charles Cowell
Sue and W. Allen Heafner • HP Enterprises Services, LLC • Jim Jarratt
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Mr. and Mrs. Mark P. Ross • Nina Salamon • Thomas and Vickie Strange

Thank You!
HNC Travels Across the State

January has been a busy month already for HNC but we wouldn’t want to start the New Year off any other way! Within a week and a half, Hemophilia of North Carolina had the pleasure of hosting five educational dinners across the state for our members. HNC’s Executive Director, Charlene, had an opportunity to catch up with old friends and make new ones at each of these five dinners. She was also able to hear more about what the community would like to see in 2014.

January 3rd (Durham), 4th (Clinton), and 9th (Concord)
Healthcare Reform and the Insurance Marketplace
Sponsored & Presented by: Baxter International Inc.

With over 70 people at our first dinner in Durham, we knew this topic would be of great interest to members of HNC. We heard an overview of healthcare in 2014, learned how changes in healthcare may affect us in NC, and discovered ways that we can stay informed. We also discussed the importance of advocating at the state and national level. Don’t forget to save the dates for the NHF’s Washington Days (Feb 26-28) and HNC’s 2014 Legislative Day (May 20)!

January 10th (Cary) and 11th (Charlotte)
Navigating Financial Aid & the Scholarship Process
Sponsored & Presented by: Biogen Idec Hemophilia

It’s that time of year again! As we learned at these dinners, financial aid and scholarships can have a huge impact on your education costs. Understanding the grant, scholarship, and loan processes will help students long after they’ve finished their schooling. We saw the real costs associated with going to school, which only helped reinforce the importance of financial aid and scholarships. We left the dinners with invaluable tools and resources.

We are very grateful to our supporters who make these educational programs possible. Please keep connected with HNC to find out about future events. Also, let us know if there’s anything specific you want to hear about as we plan our educational events for 2014.

HNC’s Lucky Day at Local HP Agency Fair

As a member of Community Health Charities (CHC), Hemophilia of NC was invited to join CHC at an agency fair for Hewlett-Packard (HP) in Raleigh on November 6th. This was a local Employee Giving Campaign kickoff event for HP and included door prizes, bake sales, and raffles. HNC’s President, Steve Peretti, was in attendance to bring awareness of bleeding disorders and to educate attendees of the event.

The biggest surprise of the day was when it was announced that all bake sale and raffle proceeds would be donated to one of the non-profit organizations in attendance. It must have been HNC’s lucky day because we won the raffle and got to take home $400! We want to sincerely thank CHC and HP for giving us this opportunity. We also want to thank all of the HP employees for their support.
$3 Million NIH Grant Awarded to Study Von Willebrand Disease

Researcher to Create New Tests to Identify Bleeding Disorder

By Maureen Mack

The Medical College of Wisconsin has received a four-year, $3 million grant from the National Institutes of Health’s National Heart, Lung and Blood Institute to improve the diagnostic tools for Von Willebrand Disease, a commonly diagnosed bleeding disorder that is over diagnosed in some populations, yet under diagnosed in others.

Robert R. Montgomery, MD, professor of pediatrics (hematology) and an investigator at the Children’s Hospital of Wisconsin Research Institute; and Thomas C. Abshire, MD, professor of pediatrics and medicine, senior investigator at the Blood Research Institute at BloodCenter of Wisconsin, and an investigator at the Children’s Hospital of Wisconsin Research Institute, are the primary investigators of the grant. Both Dr. Montgomery and Dr. Abshire see patients at Children’s Hospital of Wisconsin.

Von Willebrand Disease (VWD) is a bleeding disorder that affects the blood’s ability to clot. A protein called

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ON THE HEALTH FRONT

$3 Million NIH Grant Awarded to Study Von Willebrand Disease

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Von Willebrand factor is responsible for clotting; in VWD, patients either have low levels of the protein, or the protein doesn’t work well.

In some groups, particularly women with heavy menstrual bleeding, VWD is under diagnosed. However, it may be over diagnosed in the general population.

In this project, which is a collaborative effort between MCW, Children’s Hospital, and the BloodCenter of Wisconsin, the research team will evaluate the tools currently used to diagnose VWD for their effectiveness in identifying the disease. The results will be used to develop new screening tests, including tests that will identify the different types of VWD (up to 20% of individuals with VWD have a variant of the disease). Additionally, quantitative bleeding scores will be evaluated for their effectiveness at predicting bleeding risk.

Ultimately, this project is focused on improving the fidelity, clinical utility, and comparative effectiveness of VWD diagnosis in subjects being evaluated for a clinical bleeding disorder.

October 7, 2013, Medical College of Wisconsin, www.mcw.edu

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FDA Approves Two New Treatments for the Hepatitis C Virus

Hepatitis C is a viral disease that causes inflammation of the liver that can lead to diminished liver function or liver failure. As many as 80% of people receiving factor products to treat hemophilia prior to 1992 were infected with hepatitis C virus. Most people infected with the virus have no symptoms of the disease until liver damage becomes apparent, which may take several years. Most of these people then go on to develop chronic hepatitis C. According to the Centers for Disease Control and Prevention, about 3.2 million Americans are infected with the hepatitis C virus.

On November 22, the U.S. Food and Drug Administration approved Olysio (simeprevir), a new therapy to treat chronic hepatitis C virus infection.

Olysio is a protease inhibitor that blocks a specific protein needed by the hepatitis C virus to replicate. It is to be used as a component of a combination antiviral treatment regimen. In clinical studies, Olysio was evaluated in combination with peginterferon-alfa and ribavirin, two drugs also used to treat hepatitis C virus infection. Olysio is intended for adults with compensated liver disease (a diseased liver that is still functioning), including cirrhosis, who have not received treatment for their infection (treatment naïve) or for whom previous treatment has not been effective (treatment experienced).

“Olysio is the third FDA-approved protease inhibitor to treat chronic hepatitis C virus infection, and provides health professionals and patients with a new, effective treatment for this serious disease,” said Edward Cox, M.D., director of the Office of Antimicrobial Products in the FDA’s Center for Drug Evaluation and Research. Olysio was reviewed under the FDA’s priority review program, which provides for an expedited review of drugs that, if approved, would provide safe and effective therapy when no satisfactory alternative therapy exists, or offer significant improvement compared to available therapies.

The safety and effectiveness of Olysio were evaluated in five clinical studies. The studies were designed to measure whether a participant’s hepatitis C virus was no longer detected in the blood at least 12 weeks after finishing treatment (sustained virologic response), suggesting a participant’s infection had been cured.

Results showed 80 percent of participants given Olysio plus peginterferon-alfa and ribavirin achieved sustained virologic response, compared to 50 percent of participants receiving peginterferon-alfa and ribavirin alone. In one of the studies with participants whose infection returned (prior relapsers), 79 percent receiving Olysio plus peginterferon-alfa and ribavirin achieved sustained virologic response compared to 37 percent of participants receiving peginterferon-alfa and ribavirin alone.

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FDA Approves Two New Treatments

Another study examined Olysio’s safety and effectiveness in treatment-experienced participants, including prior relapsers, those who partially responded to prior therapy (partial responders) and those who did not respond to prior therapy (null responders). Adding Olysio improved response rates in each of these subgroups compared to peginterferon-alfa and ribavirin alone.

A reduction in Olysio’s effectiveness was observed in participants infected with the genotype 1a hepatitis C virus with an NS3 Q80K polymorphism, a strain of the hepatitis C virus commonly found in the United States. Olysio’s drug label includes a recommendation to screen for the presence of the strain prior to beginning therapy and to consider alternative therapy if the strain is detected.

Olysio is marketed by Janssen Pharmaceuticals, based in Raritan, N.J. Victrelis is marketed by Whitehouse Station, N.J.-based Merck, and Incivek is marketed by Cambridge, Mass.-based Vertex Pharmaceuticals.

On December 6, 2013, the U.S. Food and Drug Administration approved Sovaldi (sofosbuvir) to treat chronic hepatitis C virus (HCV) infection. Sovaldi is the first drug that has demonstrated safety and efficacy to treat certain types of HCV infection without the need for co-administration of interferon.

“Today’s approval represents a significant shift in the treatment paradigm for some patients with chronic hepatitis C,” said Edward Cox, M.D. Sovaldi is the third drug with breakthrough therapy designation to receive FDA approval.

Sovaldi is a nucleotide analog inhibitor that blocks a specific protein needed by the hepatitis C virus to replicate. Sovaldi

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FDA Approves Two New Treatments

is to be used as a component of a combination antiviral treatment regimen for chronic HCV infection. There are several different types of HCV infection. Depending on the type of HCV infection a patient has, the treatment regimen could include Sovaldi and ribavirin or Sovaldi, ribavirin and peginterferon-alfa. Ribavirin and peginterferon-alfa are two drugs also used to treat HCV infection.

Sovaldi’s effectiveness was evaluated in six clinical trials consisting of 1,947 participants who had not previously received treatment for their disease (treatment-naive) or had not responded to previous treatment (treatment-experienced), including participants co-infected with HCV and HIV. The trials were designed to measure whether the hepatitis C virus was no longer detected in the blood at least 12 weeks after finishing treatment (sustained virologic response), suggesting a participant’s HCV infection has been cured.

Results from all clinical trials showed a treatment regimen containing Sovaldi was effective in treating multiple types of the hepatitis C virus. Additionally, Sovaldi demonstrated efficacy in participants who could not tolerate or take an interferon-based treatment regimen and in participants with liver cancer awaiting liver transplantation, addressing unmet medical needs in these populations.

Sovaldi is marketed by Gilead, based in Foster City, Calif. Olysio is marketed by Raritan, N.J.-based Janssen Pharmaceuticals.

FDA News Release, November 22, 2013:
“FDA approves new treatment for hepatitis C virus”

FDA News Release, December 6, 2013:
“FDA approves Sovaldi for chronic hepatitis C”

Source: http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/
Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. Your dollars make a difference.

Please make checks payable to Hemophilia of North Carolina. We are a 501c(3) non-profit organization, so your donation will be tax deductible to the extent allowed by law. We will send you a receipt for tax purposes.

You may also donate online at [www.hemophilia-nc.org](http://www.hemophilia-nc.org) with your credit card.

Thank you!
Announcing...

Hemophilia of North Carolina’s 10th Annual

Charity Golf Tournament

Friday, April 25, 2014

The Preserve at Jordan Lake
Chapel Hill, NC

Beat the Pro
Back this year, special guest
Perry Parker

Monies collected will be used to provide financial assistance, scholarships, and educational programs for families living with bleeding disorders.

A percentage of proceeds from this tournament will be donated directly to funding research toward better treatments and cures.