

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2014

Why I Am a Part of HNC

By Sharon Sebolt

Ten years ago (2004), I traveled to Guatemala City to adopt Leo, a very sweet and loving 3½ years old son. Leo and I spent the next six months transitioning. Leo went from a rather isolated world into one of having a mother, a nanny, toys and a bed that were his and his alone, going outside to play, discovering all kinds of food and activities, and of course, getting regular medical care. I adopted Leo knowing that his previous three-year history was a blank slate – no family or medical history is available. While Leo and I relished our new life together, he experienced occasional swelling and pain in his ankles and knees, as well as multiple nosebleeds each week. In April 2005 we moved to North Carolina to be closer to family (and away from the hustle and bustle of the city). Within a few weeks of moving to Durham, Leo began limping and complaining of so much pain in his right ankle; I took him to the emergency room. Leo's ankle first was splinted and he was given high doses of Ibuprofen; his ankle was then casted for several weeks in hopes that the injury could heal.

Over the next several months, Leo's nosebleeds continued and increased to several times a day – to the point where I was buying multiple boxes of Kleenex every week. Finally, Leo's pediatrician

ordered bleed-time tests and he was referred to the Hemophilia Treatment Center at University of North Carolina, where he was formally diagnosed with Hemophilia A, Mild Type, as well as Anemia. Leo was 4½ years old at the time and I realized he had been suffering from muscle and joint bleeds without treatment since birth. The Hemophilia diagnosis was shocking and terrifying but the mystery behind Leo's injuries and pain was uncovered. I spent the next few years wielding a very protective shield over Leo and took him often to the emergency room, sometimes once a month, in fear that he might have sustained a head injury. Gradually, I was able to more accurately grasp how injuries might affect Leo's body. And that's when I heard about Hemophilia of North Carolina. The more confident I became with Hemophilia and how it affected Leo, the more willing I became to get involved in the greater bleeding disorders community.

Personally, I have been challenged by several issues related to Leo's diagnosis – lifestyle, health care, finances, treatment, and education to name just a few. HNC has been critical in providing for me the information and/or resources we needed in order

Continued on page 6

Meet Daniel, HNC's Summer Intern

Daniel is from Guadalajara, Jalisco, Mexico. He is 21 and is currently studying Business Administration and Management at Panamerican University. This experience is totally new for him because he has worked in for-profit companies; nevertheless, he wants to learn more about the non-profit sector. His hobbies include golf, soccer, exercise, hanging out with friends, family and Allie. He is in love with his fiancée Allie. He is also taking a course in image consulting. Daniel is glad to be here at HNC and hopes to be very helpful by contributing an important role to the organization.



Save The Date

HNC Teen Retreat
Asheboro, NC
July 25-27, 2014

HNC Family Retreat
Pine Knoll Shores, NC
August 10-12, 2014

HNC Walk Kickoff Event
Jordan Lake
Chapel Hill, NC
August 16, 2014

HNC Adult Retreat
Parkton, NC
September 6-7, 2014

HNC Blood Brotherhood Event
Kure Beach, NC
September 13-15, 2014

NHF Annual Meeting
Washington, DC
September 18-20, 2014

HNC's 2014 Hemophilia Walk
Morrisville, NC
October 11, 2014

HNC Statewide Yard Sale
October 25, 2014

HNC SOAR Retreat
Winston Salem, NC
November 7-9, 2014

HNC Holiday Celebration
Winston Salem, NC
December 6, 2014



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Morrisville, NC 27560
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org

MISSION STATEMENT

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

Contact Numbers

Hemophilia of North Carolina

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

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC

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

About This Publication

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

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

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

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.hemophiliafed.org

American Pain Foundation (APF)

1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
painaid.painfoundation.org

American Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

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

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www.inalex.com

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www.kelleycom.com

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www.patientnotificationsystem.org

Patient Services Incorporated (PSI)

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

World Federation of Hemophilia

1-800-520-6154
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.

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.



From the HNC Office



*Charlene Cowell,
Executive Director*

We're continuing to grow – both in members and staff! Since the last newsletter was published, we've held more than 12 events, expanded our staff to five, and developed plans to enhance our programs and services for the community. We hope we can count on your support to help us continue these efforts.

Each event gives us an opportunity to hear from members like you about how we're doing, but we want to take it a step further. We'd like to meet with you outside of HNC events to hear your story – find out what needs you have, and how HNC can support you and your loved ones. If you have the time and are interested in sharing with us, we would love to have a conversation. We'll travel to you!

Within this edition of *The Concentrate* you'll have an opportunity to get to know our new staff members: Daniel León, Jamie Strom and Ritu Mala. You can check out Rita and Jamie's bios below. Each of us brings unique skill sets and passions to the organization and community. As a team, we hope to continue to build on the

Ritu Malla, Intern

Currently a full-time student at UNC Chapel Hill, Ritu is a young, ambitious student interested in the profession of health. Along with her passion for chemistry, she enjoys interacting and being involved with the community. Although a fairly new addition to HNC, she hopes to contribute as much as she can, and gain a lifetime of experiences. She enjoys relaxing and hiking with her friends in her spare time, and works part-time as a restaurant server.



success of our current programs and utilize our diverse experiences to look at new opportunities.

There are a lot of fantastic HNC events coming up in the next few months. We encourage you to take a look at those programs highlighted in this edition of *The Concentrate* as well as check the website for updates and upcoming events. This is also a great time to make sure we have your most updated email address so you'll receive the latest information available. If you're not getting emails from HNC, please give us a call or send us an email and we'll update our records.

It just takes one event to get connected. Many families and individuals have formed invaluable relationships with others they met at an HNC event. Please come out and join us to make your own connection today!

*Warmest Regards,
Charlene and Lakia*



*Lakia Poole,
Assistant Director*

Jamie Strom, Bookkeeper

Jamie Strom is currently the Operations Manager at the Morrisville Chamber of Commerce. Jamie also conducts bookkeeping for a few small businesses in her spare time. She has a passion for watching small companies grow and being a part of its success. She is a rare native of Raleigh, NC. Jamie graduated from Wake Technical Community College in 2011 with an A.A.S. in Accounting. She has been volunteering with HNC since November 2012, and is now working part-time in her bookkeeping role. Her previous volunteering opportunities include Meals on Wheels, Triangle Family Services and other organizations in the Triangle area. Strom has a six-year-old son that drives her to be more successful; to show him anything is possible. In her spare time, you can find Jamie involved in extracurricular activities with her son, cross-stitching, reading or socializing with amazing friends and family.



The new HNC crew!



41st HNC Annual Meeting May 3

HNC had a fantastic turnout for the Annual Meeting, located this year in Charlotte. With 180 attendees present, members and community partners enjoyed a day filled with beneficial resources, fun and opportunities to connect and learn.

A well-known speaker to HNC, Pat “Big Dog” Torrey, facilitated our opening session. Pat has been a part of our community for quite some time and always brings exciting, innovative ways to think about how we approach our everyday lives. He led the morning crowd with entertaining icebreakers and other activities.

The day continued with a range of breakout sessions for our HNC programs (Blood Brotherhood, HOPE, SOAR) and topics including life transitions, advocacy and stress management. The day concluded with a social outing at Strike City Bowling in downtown Charlotte. Members enjoyed the opportunity to gather information and celebrate connections, both old and new.



An evening at Strike City was the perfect way to end the day!

2014 HNC Volunteer Dinner May 2nd

On May 2nd in Charlotte, HNC hosted its annual Volunteer & Special Guests Dinner, recognizing the dedication and valuable work that HNC members have contributed to the organization and the larger bleeding disorders community.

The dinner featured a keynote address by renowned facilitator and public speaker Pat Torrey. Pat shared a very inspiring and thoughtful message, complete with humor and insight.

The success of HNC comes from the tireless efforts of so many individuals, from our members, to community partners and supporters. Special thanks to our Platinum Sponsors: Baxter International Inc., Bayer, Novo Nordisk and CSL Behring. HNC is immensely grateful for all that you do to provide effective resources and services to our members!

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2014 HNC Annual Meeting:

Platinum Sponsors

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Matrix Health • MedProRx • Octapharma
Specialty Therapeutic Care
Walgreens Hemophilia Services



The kids lean in to learn a science experiment.



Folks had a great time at this year's Meeting!

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2014 HNC Charity Golf Tournament:

Tournament Sponsors



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2014 HNC Golf Tournament

April 25

HNC hosted its 10th Annual Charity Golf Tournament this year at The Preserve at Jordan Lake in Chapel Hill. Over 70 golfers participated in the tournament, with net earnings of nearly \$27,000. Proceeds help support valuable HNC programs and services to community members.

After registration and grabbing their boxed lunch, golfers set off for a day on the course. While a storm sent the golfers in a bit early, they did get to enjoy a good while on the green and it didn't dampen the spirit of the day! Players had a chance to test their skill and Beat the Pro, Perry Parker, who joined us again this year. Our many thanks to CSL Behring for sponsoring Perry as well as their continued support of our tournament.

The event featured an impressive array of raffle prizes, from a sunset sailing trip, to whitewater rafting, to dozens of gift cards for great stores and restaurants.

Apex Wings catered the dinner, and guests enjoyed some evening music on the deck, performed by Penni and the Squirrel.

A very special thanks to the golfers, sponsors and volunteers who helped make our 10th Annual Tournament a huge success!

Congratulations to the winners of our tournament:

- 1st Place: **Moore Printing**
- 2nd Place: **Drugco**
- 3rd Place: **Kelly's NC Erosion Control**



Golf pro Perry Parker helps a young golfer with his swing.



Getting ready for the game!



Todd Whitaker of Moore Printing, an HNC community partner for over 7 years, winning big!

Why I am a Part of HNC *Continued from page 1*

come through successfully to the other side of each battle. Leo was also diagnosed with severe Attention-Deficit Hyperactivity Disorder (ADHD) at the age of 6 and as you might imagine, the combination of having both ADHD and a bleeding disorder presents an additional challenge in keeping Leo's injuries to an acceptable level. My guesstimate is that Leo experienced (and still does) 95% of his joint and muscle bleeds during periods of time when he was either undermedicated or not medicated at all.

Educating Leo's teachers and classmates about Hemophilia, the importance of treatment, and the benefits of everyone being on the "same page" was also of great concern to me. HNC, along with Leo's HTC, was instrumental in helping to devise more appropriate activity and treatment plans, and educational materials to use in presentations to the school. In line with Leo's dual diagnosis of ADHD and Hemophilia A, it is worthwhile to note that I have experienced some bias with regard to people's perception of what mild form versus moderate or severe forms of bleeding disorders should necessitate in terms of treatment

and funding. For example, Leo has experienced several muscle and joint bleeds when participating in activities that range from extremely low risk to higher risk activities. Just like someone with severe Hemophilia, Leo can suffer a joint bleed from jumping off a swing; the difference is that Leo can jump off a swing twenty times before he sustains a bleed. HNC lessened my concerns about this preconception in its full-gathering of information and encompassing approach to *all* persons affected by *all* bleeding disorders. HNC informs me about current and upcoming research which targets not only treating more severe forms of bleeding disorders, but also research projects involving treatment options for Mild and Moderate types. Over the years, my worry has waned in great part because of HNC's compassion and support. Mild Hemophilia is a blessing; Leo does not require prophylactic treatments unless surgery or significant dental work is planned; and prophylactic treatment would be difficult emotionally, physically, and certainly, financially.

HNC is one of the most important aspects of my support network. They welcomed me openly from the very beginning! Each and every time I have had a question, HNC is there: about how to find additional information about the quirks surrounding mild Hemophilia; where to look for additional financial resources to help in paying bills, securing clotting factor and supplies. They helped guide me through the often scary and complex voyage of diagnosis, education on treatments, and health care options – all of this with knowledgeable compassion. One thing I appreciate so much is the gratitude HNC expresses for just the little things we all do to help support the community. The best part of HNC membership is being a part of the family, a family that truly understands the challenges we face each and every day; appreciates the lengths to which we go in order to keep our loved ones safe, and provided with the best health care available; and, the commitment we have to each other through educational, emotional, informational, and financial support.

Initially, I was scared to get involved. Perhaps these statements sound familiar: "I don't know enough," or "I don't have anything of value to contribute," or "I'm not the kind of person who 'does stuff'," or maybe "That doesn't concern me." I'm here to assure you that you know plenty! You have everything to contribute! And, there is always something that concerns you! And just like within the walls of a traditional family, the more members who communicate with one another, the better the family thrives as a whole.

Sharon Sebolt is the mother of a 13 year-old son with Hemophilia A (mild) and is a member of the Board of Directors of Hemophilia of North Carolina.



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Gettin' in the Game Golf Clinic

April 26

CSL Behring presented their *Gettin' in the Game Golf Clinic* this year at the Rocky River Golf Club in Concord, NC. Boys & girls ages 7-17 could attend to brush up on their golfing skills and meet others in the community.

PGA tour pro Perry Parker participated as guest instructor. Perry is a favorite here at HNC, having now been a part of many of our golf tournaments, including this year's Charity Golf Tournament event.

The youth had a great time at the event, sharing a fun game of golf while receiving tips from Perry on the best ways to improve their techniques. During a poignant moment, Perry shared his own experiences regarding hemophilia and his golf career.

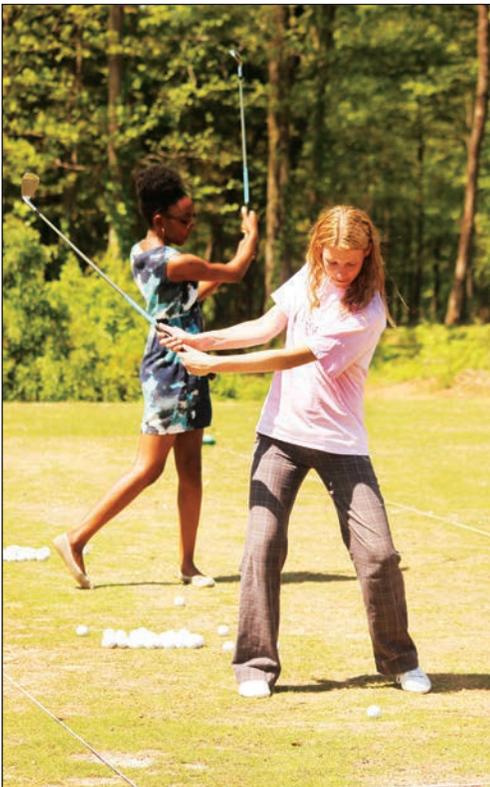
Developed by CSL Behring, the *Gettin' in the Game Golf Clinic* is a one-of-a-kind program, designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to bond over a day of golf and provides education and information-sharing opportunities for participants and their families.



A promising group of golfers pose with pro Perry Parker.



Youth received a chance to learn the tricks of the trade.



Even HNC staff got in on the fun!



2014 HNC Legislative Day

May 19 - 20

HNC members put their collective voice to powerful use at this year's Legislative Day event. A two-day occasion, the event featured a dinner on May 19th, complete with a panel discussion on effective advocacy. Attendees had a chance to field questions with panelists about the best approach when communicating with their state representatives.

Legislative Day (May 20th) also went well. Members met with their elected officials, and provided information about HNC, and shared their own personal stories as well as HNC's position on Medicaid expansion and reform.

The Affordable Care Act (ACA) has given many people with bleeding disorders access to medical care that most healthy people may take for granted. By advancing tax refund subsidies even people of modest means can afford insurance that covers all essential medical benefits. However, the Supreme Court's decision to make Medicaid expansion by the states optional has left an unintended gap in health care coverage for lower income citizens.

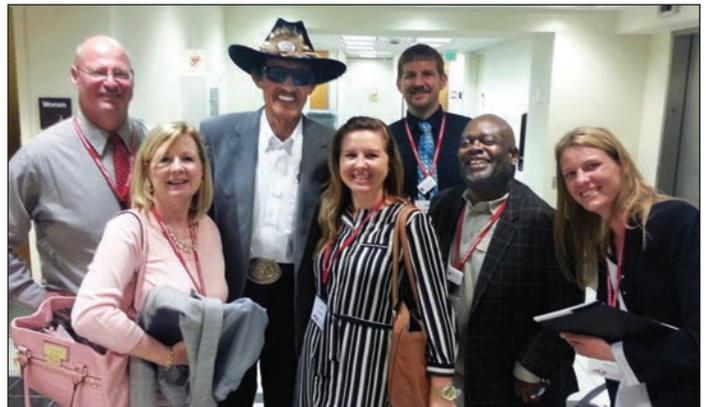
The ACA subsidies apply on a sliding scale to people who earn at least 100% of the federal poverty level, but at most 400% of the federal poverty level. The statute, anticipating that people below the poverty level would get Medicaid, did not extend the subsidies to them. Because North Carolina followed a minority of states that did not expand Medicaid, those with a smaller and/or limited annual income are unable to afford the policies offered on the federal health benefit exchange.

For example, a single person making minimum wage in North Carolina must work 31 hours a week to earn the federal poverty level (\$11,490/year) and qualify for the ACA subsidies. A person working only 30 hours a week does not make the poverty level and does not qualify for subsidies. His policy costs the same as a wealthier person making over \$40,000 a year.

The Senate and House have introduced a bill, S.B. 730 and H.B. 1083 respectively, that addresses the expansion of Medicaid to include low-income citizens that are missing health coverage. HNC is proposing that our state's representatives consider supporting this legislation so that everyone in North Carolina has access to affordable health care.



Attendees receive advocacy training at a dinner prior to Legislative Day.



Members of the group bumped into Richard Petty!



Arriving at the State Legislative Building

Hemophilia of North Carolina is grateful to



Bayer HealthCare



CSL Behring

Biotherapies for Life™

for their support of Legislative Day 2014.

Cooking for Camp Carefree

May 28

In only a few weeks, Biogen Idec employees were able to raise \$5,000 for Hemophilia of North Carolina to help support Camp Carefree by hosting bake sales in their office. HNC has developed a great relationship with the Women’s Innovation Network (WIN) Chapter at the Biogen Idec RTP location and these empowered women truly made a difference in the lives of many children looking forward to camp this year. Through their efforts, they have raised much more than \$5,000 – they have raised awareness!

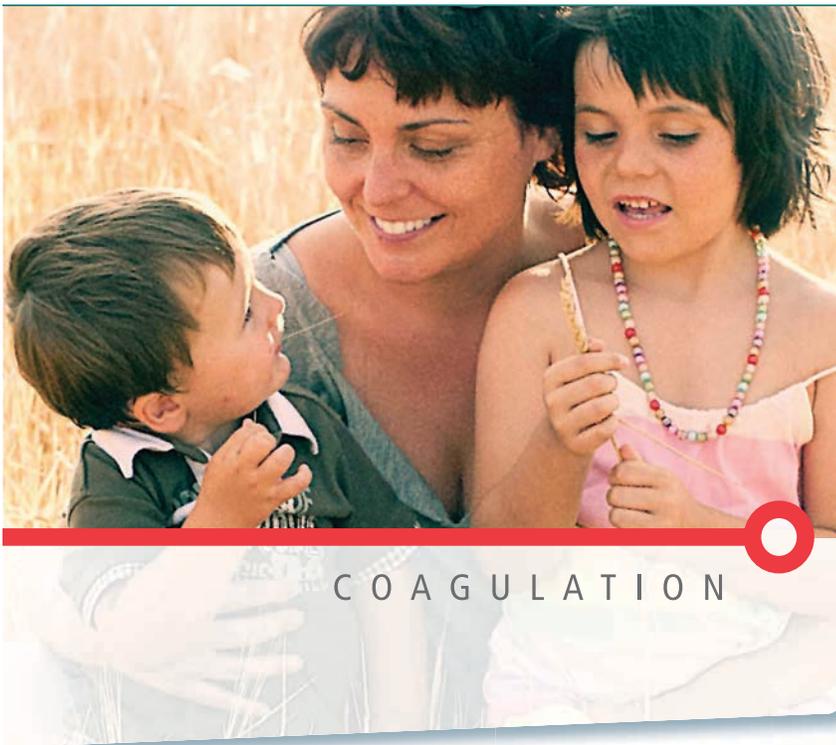
HNC Executive Director Charlene Cowell was joined by HNC members Matt Igelman and George McCoy to speak at the Biogen Idec RTP building and tour the facilities. In addition to warm hospitality, they provided us a platform to speak, in front of 150+ people, on the HNC community, its history and the vision for the future. Afterwards, all smiling ear-to-ear as Biogen Idec presented a \$5,000 check that will be sent to Camp Carefree.

HNC is fortunate to have three camps that offer opportunities for children affected by bleeding disorders – Camp Carefree, Camp Rainbow, and Victory Junction. Camp Carefree has been a part of our community since 1986 and continues to offer weeklong camping experiences for children in NC and neighboring states.

We thank Biogen Idec, especially the women of WIN, for all of their extraordinary efforts to help us support the camps that support our next generation of advocates!



Biotherapies for Life™ CSL Behring



COAGULATION

At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.

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www.CSLBehring-us.com COA13-08-0045 9/2013

Community Partner Spotlight: *Dan Litz*

For over 20 years, HNC has been a member of Community Health Charities of North Carolina (CHC-NC), an affiliate of Community Health Charities of America (CHC), a federation of the nation's top health charities.

CHC-NC represents you in federal, state, municipal, and private sector workplace giving campaigns around the state. HNC is listed among the nation's top charities at these campaigns. As a result, HNC has received many thousands of dollars from employees who designate their workplace giving contributions to us.

At the CHC-NC annual membership meeting in May, representatives of the assembled charities surprised Executive Director Dan Litz with an award honoring him for his twenty years at the helm. Dan is renowned for his work ethic, integrity,

honesty, fairness, and his compassion for people with difficult diseases and disabilities, and his passion for health charities.

HNC member Kathy Register, who has served as Treasurer and President of CHC-NC, was there representing HNC.

Visit www.healthcharities.org/Our-Charities for a list of CHC charities and northcarolina.healthcharities.org to visit CHC-NC's local website.

HNC is On the Road Again

In June HNC hosted educational dinners to provide an opportunity for members to come and learn different aspects about the treatment and management of bleeding disorders. Held in different cities, the dinners featured presentations from various companies, including Novo Nordisk, Baxter International Inc. and Biogen Idec.

The dinners were very successful, and all were held within one week! While it kept the HNC office pretty busy, it was well worth it. It's always great to have members come together to learn, share and enjoy each other's company.

If there are events, including educational dinners, that you would like to see in your area, please don't hesitate to talk to HNC staff about it. You can always reach us by phone toll-free at 800-990-5557, or by email at info@hemophilia-nc.org.



Executive Director Dan Litz (right) receives award from Jeff Furst, CHC-NC Past President on behalf of member charities

2014 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2014. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Donors

Sue and W. Allen Heafner • Scott and Carrie Kimbrough • Charles and Sue Cowell
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Community Health Charities of NC • Launch That Event, LLC
Colleen McKay • Donald Pulliam • Mark Miglarese

In Loving Memory of Edwin Wilson

Mr. and Mrs. Donald Franklin

In Loving Memory of Matthew Speight and Monroe Poplin

Rockwell Ladies Auxiliary 485

In Honor of Andy Blaquiére

John Hamilton, Jr.



Upcoming Events



2014 HNC Walk Kickoff Event

August 16, 2014
Chapel Hill, NC

Get ready for the 2014 Walk Kickoff! This year's event will be held at beautiful Jordan Lake Park, on Saturday, August 16, and we have plenty of fun activities in store. This year's theme is Carnival at the Kickoff, and will feature bingo, water balloon toss, relay races, a magic show and much more!

The Kickoff is an opportunity for those participating in the HNC Walk to get information about registering their team, raising

funds for the Walk, ordering team T-shirts and connecting with fellow supporters. Walk team captains are encouraged to attend, and feel free to invite your team members.

Check out the HNC website, www.hemophilia-nc.org, for information and updates on the Kickoff event. For questions, feel free to contact Lokia Poole, HNC Walk Manager, at the office at 800-990-5557.

HNC Family Retreat

August 10-12, 2014
Pine Knoll Shores, NC

It's nearly time for our annual Family Retreat! Come out and join us at the Outer Banks August 10-12 at the Trinity Center in Pine Knoll Shores, NC. We invite families with children who are affected by a bleeding disorder to join us for a fun-filled, educational retreat at the beach. The Family Retreat is a time to gain practical tools, connect with other families, share your own experiences and most of all – have fun!

Through feedback from prior retreats and interactions at HNC events, we have gained valuable insight into the needs of families. Through this information, we have put together a new format and

agenda that we feel provides resources along with the opportunity to meet others. We are looking for families that will be engaged and active during the educational sessions to attend the retreat.

We are excited to be featuring a number of excellent speakers and program facilitators this year and include a variety of programs for adults and children. Of course, we'll have plenty of fun and free time too!

Look for more information and invitations soon!

Blood Brotherhood Retreat

September 13-15, 2014
Kure Beach, NC

The Blood Brotherhood will have their annual Retreat at Kure Beach this September. This event is always a great way to meet other Blood Brothers, share stories, and enjoy some sun. As a social retreat this year, attendees will be able to spend their time getting to know one another.

Priority for the retreat is given to Blood Brothers who have attended at least (1) Blood Brotherhood program/event this year, but we encourage all men with a bleeding disorder to register. Must be 21 and older to attend. Check out the HNC website at www.hemophilia-nc.org for information and upcoming communications.

NHF Annual Meeting

September 18-20, 2014
Washington, DC

Registration for the 66th Annual Meeting of the National Hemophilia Foundation (NHF) is now open. The conference, themed 'Nothing About Us Without Us', will be held September 18-20, 2014 in Washington, DC. The three-day meeting will feature a variety of educational topics, including sessions regarding the basics of hemophilia, inhibitors, healthy cooking, music therapy for pain management, women and bleeding disorders, and much more.

To register, visit the NHF website at www.hemophilia.org, and select 'NHF Annual Meeting' under the "Events and Meetings" tab. For questions, contact the NHF Meeting Hotline, at 800-424-2634, ext. 4.

Upcoming Events continued on page 12

Upcoming Events *Continued from page 11*



HNC Walk Event

October 11, 2014
Morrisville, NC

Be sure to mark your calendars for the 7th Annual Hemophilia Walk! The largest fundraising event for HNC is taking place on Saturday, October 11th at Lake Crabtree County Park in Morrisville. Registration begins at 9:00am and the walk is 10:00am.

Planning is well underway and to date, we've raised over \$17,000 in local support and our goal this year is \$100,000 with 1000 walkers!! We welcome our Walk Chair Team this year, Team Hulk Smash, led by captain Gillian Schultz.

The Hemophilia Walk is the National Hemophilia Foundation's (NHF) largest event dedicated to finding better treatments and cures for bleeding and clotting disorders, and to preventing the complications of these disorders through awareness, education, advocacy and research. The walk in North Carolina is a collaborative effort between NHF and Hemophilia of North Carolina (HNC). The North Carolina chapter is proud to be one of 31 locations around the country participating in this program. 100% of proceeds raised locally will go directly to HNC and help our chapter continue to provide programs and services to our local community.

The day will feature a 5K walk, food, music, games and all-around fun for family and friends (even the 4-legged ones). It's never too early to get involved — start your walk team today! Visit our webpage at www.hemophilia-nc.org to get information on registering for the Walk and creating a fundraising team. The site features information for sponsors, teams and volunteers.

Printed Sponsorship and Team Captain Packets are also available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. We are looking forward to another great event this year and hope to see everyone there!

HNC Adult Retreat

September 26-28, 2014
Parkton, NC

Feel like a kid again at HNC's Adult Retreat! Join us in Parkton, NC for three days of exciting activities, and chances to learn and meet with other members. The Retreat will be held at the Rockfish Camp and Retreat Center. The Retreat is designed for adults ages 18 and older, who are either affected by a bleeding disorder or have an immediate family member that has a bleeding disorder.

The focus this year will be developing life skills applicable to not only the management of a bleeding disorder, but the management of all aspects of daily living.

Of course, no retreat is all work and no play! The Rockfish Center features exciting chances for adventure. Keep your eyes open for updates from the HNC office on details.

HNC SOAR Retreat

November 7-9, 2014
Winston Salem, NC

SAVE THE DATE! HNC's SOAR program is having their annual Retreat on November 7-9 at the beautiful Graylyn Conference Center in Winston Salem. The Retreat will focus on providing content that gives attendees a better understanding of their bleeding disorder, as well as their child's bleeding disorder. Participants will also learn about the variety of available resources to enrich their lives.

The retreat will be open to women affected by a bleeding disorder, female caregivers of a girl with a bleeding disorder and girls 12 and older diagnosed with a bleeding disorder.

SOAR is a program of HNC, designed to increase the knowledge, awareness and support for girls and women with bleeding disorders. To find out more about SOAR, please contact us at soar@hemophilia-nc.org.

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Conoce a Daniel, Becario de Verano en HNC



Daniel es de Guadalajara, Jalisco, México. El tiene 21 años y actualmente está estudiando administración de empresas.

Esta experiencia es totalmente nueva para el ya que el ha trabajado en compañías con fines de lucro, sin embargo el quiere aprender más sobre el sector sin fines de lucro.

Sus hobbies son jugar golf, futbol soccer, ejercicio, pasar tiempo con amigos, familia y Allie. El esta enamorado de su prometida Allie. Además, esta tomando cursos para consultoria de imagen.

El esta contento de estar en HNC y espera ser de mucha ayuda y poder contribuir cosas importantes a esta organizacion.

Cena educativa - Conceptos básicos de Hemofilia

El pasado Viernes 20 de Junio en la Oficina de Hemofilia de Carolina del Norte (HNC) ubicada en Morrisville, NC, se llevó a cabo la primera de las dos cenas educativas que HNC organizó para los miembros del programa de Unión Latina de Hemofilia. Karla Zevallos de la compañía Baxter International, Inc. presentó el tema “Primero hechos: Conceptos básicos de Hemofilia.”

Los miembros que asistieron pasaron un rato muy agradable y disfrutaron de una deliciosa cena italiana. Los niños se divertieron mucho dibujando y conviviendo con Daniel Leon, nuestro pasante de verano.

La sesión informativa fue todo un éxito, ya que la dinámica del árbol genealógico junto con la información ayudó a que los miembros conocieron más sobre la hemofilia.



Reportè de la Reuniòn Anual

Mi nombre es Carlos Diaz y pertenezco a la Asociación de Carolina del Norte desde hace 13 años. Este pasado Mayo fue la primera vez que asistí a una Reunión Annual. Me agrado sobre todo la buena organización del evento. Tambien me gustò la oportunidad de obtener información a través de las presentaciones y de las compañías que estuvieron en el evento. Me llamò la atención el progreso en los tratamientos y productos para la Hemofilia.

Hoy en día, el tratamiento de esta condición ya no es tan traumático como en el pasado. Ahora, los tratamientos son más efectivos y seguros. Tengo la seguridad que más adelante se encontrara una cura definitiva para todos los que se encuentran afectados por esta condición.



Save the Date!

HNC SOAR Retreat

November 7-9 • Winston Salem, NC

HNC's SOAR program is having their annual Retreat on November 7-9 at the beautiful Graylyn Conference Center in Winston Salem. The Retreat will focus on providing content that gives attendees a better understanding of their bleeding disorder, as well as their child's bleeding disorder. Participants will also learn about the variety of available resources to benefit their lives.

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SOAR is a program of HNC, designed to increase the knowledge, awareness and support for girls and women with bleeding disorders. To find out more about SOAR, please contact us at soar@hemophilia-nc.org.

Ovarian Cysts: Recognizing Symptoms and Complications

Few medical conditions mirror the pain of a burst appendix. But women with a ruptured ovarian cyst say it comes close. "I couldn't walk or put pressure on my right leg because the pain was so excruciating," says Sarah Fey, 38, who has type 1 von Willebrand disease (VWD). "I thought maybe I was having appendicitis," says the project coordinator from Gilbert, Arizona.

Therein lies the problem — confusion about ovarian cysts and their complications. Women with bleeding disorders need to know if they're susceptible to ovarian cysts and how to manage them.

Ovulation obstacles

Every month, the body prepares for pregnancy by forming a follicle, a fluid-filled sac, around the egg. Normally, the follicle breaks open, releases the egg, then dissolves. However, if the follicle fails to open or dissolve, a cyst forms. As fluid builds up in it, this follicular, or functional, cyst grows. According to the US Centers for Disease Control and Prevention (CDC), ovarian cysts are common during the childbearing years. Most go away on their own without issue.

But the situation is different for women with bleeding disorders, says Andra H. James, MD, ob/gyn at the University of Virginia School of Medicine in Charlottesville. That's because these women can bleed even during normal ovulation, when the egg is released from the follicular sac. And the bleeding can be significant. "They're at risk for hemorrhagic ovarian cysts," James says. "They can bleed into the sac itself and into the abdomen."

An emergency room visit six years ago led to the discovery that Brooke Connell, 31, was prone to ovarian cysts. "I had a hemorrhagic ovarian cyst that ruptured," says the PR/marketing specialist from Kansas City, Missouri. "When they did the ultrasound, they could see the blood around it."

Connell, who has type III VWD, was then diagnosed with polycystic ovary syndrome, the inability to produce mature follicles. To get pregnant, she's undergone treatments for infertility. "During several cycles we've had to stop the medication that stimulates the ovaries to produce more eggs because I've had large cysts on one or both ovaries," says Connell.

Ovarian cysts also occur in women with other bleeding disorders, such as hemophilia, rare factor deficiencies and platelet defects.

Subtle and serious symptoms

Mild ovarian cyst symptoms can be easily dismissed. For instance, stomach pain, bloating and a dull ache in the back can be mistaken for premenstrual syndrome. Fey experienced a cluster of such symptoms in 2013. Pressure in her abdomen was one sign. "I felt full even at times when I was hungry," she says. Needing to urinate at night was chalked up to aging. But heavier menstrual bleeding sent her to her doctor. "An ultrasound last fall revealed cysts on both sides," she says.

The larger the cyst, the more pain a woman will feel, says James. When they're about 5–10 cm (2–4 inches), they can

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Ovarian Cysts: Recognizing Symptoms and Complications Continued from page 14

begin to cause problems. Connell's was 6 cm (2 1/3 inches) when it ruptured. Ruptured cysts can cause internal bleeding, sometimes with severe pain. "Very large cysts can cause the ovary to twist on itself, but that's in extreme cases," James says. This torsion of the ovary can cut off blood supply, resulting in permanent infertility.

Treatment factors

Treatment for ovarian cysts depends on several factors. If they're small and asymptomatic, they may resolve on their own within three months or so. Although Fey currently has cysts on both ovaries, she's not anxious. "They're non-fluid-filled, so they are not a concern at this time," she says.

Sometimes conservative measures are called for when a woman has hemorrhagic ovarian cysts. "We'll try to correct the underlying bleeding problem and watch the woman very carefully in the hospital until the symptoms improve," says James. But other times surgery is needed to remove a cyst or damaged ovary, especially if there's acute pain and severe bleeding.

Preventive measures

Contraceptives can prevent ovarian cyst formation by inhibiting ovulation. The progesterone-estrogen combination pills that contain the same daily dose (monophasic), Depo-Provera injections and subdermal implants containing the hormone etonogestrel are all effective. "Only these methods are going to protect a woman from hemorrhagic ovarian cysts," says James. Progestin-only pills and the levonorgestrel-containing IUD, often prescribed for women with bleeding disorders who have menorrhagia (heavy menstrual bleeding), however, do not work, she adds.

Expanding education

Chances are, most women are not familiar with ovarian cysts. "My mom has mild VWD, but she never had cysts," Connell says. Much of her information and support have come from her hemophilia treatment center (HTC). "I am in contact

with my nurse at the HTC a lot, so if I ever have trouble, I just call her," she says. "She's been a blessing when it comes to communicating with my other doctors about the plan for me or when I should dose."

Healthcare providers also need education about the risk of hemorrhagic ovarian cysts in women with bleeding disorders. "We've educated around this over the last decade, so more of them know about it," James says. Patients can take the lead, too. "Even as a teenager, women need to begin this discussion."

HemAware, May 2014 www.hemaware.org

SOAR at the HNC Annual Meeting

The SOAR breakout session at the HNC Annual Meeting in May was a huge success this year! Many women attended, some for the first time, to come together and discuss the direction of SOAR programming, activities planned for the year, and ways to get involved in the group.

The idea for SOAR walk groups was met with an enthusiastic response. Attendees felt as though walking groups in different cities would be a great way to connect to other SOAR members, as well as reach out to girls and women who may not already be involved. Two groups were formed, in Charlotte and Raleigh, where girls and women with bleeding disorders can meet monthly to walk at a local park. To make the walk groups even more interesting, each group's walking mileage will be tracked and we'll celebrate the winning group at the HNC Walk event in October!

If you are interested in being a part of the SOAR walking group, or would like to start one of your own, please feel free to contact the HNC office at 800-990-5557, or at soar@hemophilia-nc.org.

Membership Information

For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to soar@hemophilia-nc.org.

Support • Outreach • Advocacy • Resources
An HNC Program for Girls and Women with Bleeding Disorders

SOAR's Mission Statement: *To improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.*

Blood Brotherhood Update



On April 12, 2014 the Blood Brotherhood got together for a Game Day celebration at the HNC office in Morrisville. Folks were encouraged to bring their favorite games from home, in addition to the provided video games at the event.

People also played the ever so popular Corn Hole game. A big hit at this years Game Day was the 1000 piece puzzle that was almost finished by a team of very talented puzzlers. A couple heated showdowns on NBA 2k14 later, the group enjoyed a wonderful dinner from Bonefish! This social gathering truly provided a great time for guys to share, relate, vent, and become friends. The Blood Brotherhood program is a national program for adult men, diagnosed and living with bleeding disorders. It is designed to be a multi-avenue outreach, to provide education and support, promote good health, and establish a sense of community for adult men. A big thanks to the Hemophilia Federation of America for this valuable program here in North Carolina and around the country.

For more information on Blood Brotherhood nationally, including information on the private online forum for adult men with bleeding disorders, and the online Blood Brotherhood Chat, visit: <http://www.hemophiliafed.org/programs/blood-brotherhood/>.

For more information on Blood Brotherhood locally, visit the HNC website www.hemophilia-nc.org and join our Blood Brotherhood group at our future events!



Blood Brothers were glued to their video games!



A 1,000 piece puzzle under way!

Join the 4th Annual Bayer Virtual Walk for Hemophilia!

Help your local hemophilia chapter raise sponsorship funds by participating in the 4th annual Bayer Virtual Walk for Hemophilia.

Spread the word to your friends and family. Every virtual walker brings your chapter one step closer to making a difference in the community!

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HOPE Update

By Gillian Schultz

- *Help*
- *Opportunity*
- *Partnership*
- *Empowerment*

Things have been active in the Charlotte area for the HOPE Program. On May 3, there were two HOPE sessions at the HNC Annual

Meeting. The first was an overview of the HOPE program. The second session included a roundtable discussion of what it is like raising a child with a bleeding disorder. Several families took part in the discussion. Some topics we discussed included bullying, finding appropriate daycare, and common things that parents have to deal with when raising a child with a bleeding disorder.

On June 18, HNC and HOPE partnered with Novo Nordisk to hold an educational dinner called Living Well with Hemophilia: Understanding the Challenges. The dinner was held at P.F. Chang's Bistro in Charlotte. We had a great turnout, with more than 35

people in attendance! Sue Geraghty, RN presented a great session. Both before and after the presentation, the room was buzzing with conversation as people were networking and catching up with each other. The children had a great time too, decorating picture frames and "digging" for dinosaurs.

Stay tuned for events over the summer and fall. We hope to see you at the HNC Family Retreat in August. The Family Retreat offers a number of different interesting and helpful sessions. It is a fun event for adults and kids alike! Additionally, if you have any ideas for future events that you would like to see and locations where you would like to have an event held, please let us know.

HOPE is an HNC program for families with children from birth to twelve diagnosed with a bleeding disorder. Open to any member of HNC, programs are geared towards the unique needs of these families – to educate and support them so that their children can lead fulfilling lives.

For more information, please contact me, Gillian Schultz, volunteer HOPE Program Coordinator, at gillian.schultz@hemophilia-nc.org or Lakia Poole, HNC Assistant Director at info@hemophilia-nc.org. You can also reach the HNC office at (800) 990-5557.

NCABBD Update

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) meets quarterly, our most recent meeting held in June. Many topics were discussed at the recent meeting, including:

- Hemophilia Treatment Center (HTC) Updates: HTC representatives shared that all (3) HTC have 340B programs up and running, under the leadership of Dan Dalton at UNC's center.
- HNC Advocacy: After the HNC Legislative Day, questions remain about the reconciliation of the Senate and House budgets, as well as the Governor's plans on Medicaid. Despite this outlook, discussions with the Department of Health and Human Services are promising.
- Medicare and Long-Term Care: A rising issue is accommodation for those in need of long-term care, with no Medicare coverage for factor in nursing facilities. Without this coverage, patients requiring long-term services are either kept in expensive hospital stays, must pay out-of-pocket or enroll in Medicaid. Other insurance carriers follow the example of Medicare, so this problem will increase as the bleeding disorders population ages.

NCABBD members include staff from North Carolina's Hemophilia Treatment Centers, as well as representatives from the bleeding disorders community. Hemophilia of North Carolina staff, board members, and volunteers are well represented.

Warren Jewett: *A Man of Many Talents*

Recently, HNC staff had a wonderful opportunity to visit with long-time HNC member Warren Jewett. Warren's personal and professional achievements are truly inspiring, and spending the day with him while he shared his story was a real treat. HNC is honored and grateful to have Warren as a part of our community.

Warren has managed a very successful career, from creating over 60 medical devices benefiting the lives of many around the world, to consulting for the World Health Organization, to serving as President of the National Hemophilia Foundation. Growing up with hemophilia, he has surpassed great odds and has created a powerful legacy that signifies his perseverance, hard work and passion for leaving the world better than he found it. Not one to stay idle, Warren is still busy with the labor of invention — he is 84 years old, still going strong, currently working with a team from Arizona to create a blood pressure device for veterinary medicine.



Welcome Our Newest HNC Board Members

At the HNC Annual Meeting in May, attendees were able to meet and vote on community members currently running for available seats on the HNC Board of Directors. We welcome our new board members for a two-year term effective July 1, 2014:

Dylan Clark

Dylan was diagnosed with severe hemophilia A shortly after birth. He had a multitude of complications from having fluid on the brain, failures of several central lines, and an inhibitor. He is grateful for the love and care from doctors at the Hemophilia Treatment Center at the University of North Carolina and the continued outpouring of care and support from his extended family in the hemophilia community. Dylan's desire is to help HNC continue to grow by pouring out that same care and support he received to the younger generation.

Maxine Locklear

Maxine is a native of Robeson County and enrolled in the Lumbee Tribe. She has a 12 year old son with severe factor VIII deficiency Christopher. She is a 6th grade Math Teacher in Robeson County Public Schools.

Leroy Taylor

Leroy has two children with bleeding disorders. He was first introduced to the hemophilia community in 1998 when he discovered that his now 17-year-old son had hemophilia. His family's relationship

to the community grew stronger in 2008 when they learned that their now 11-year-old daughter has von Willebrand Disease. He would like to help others in the bleeding disorders community as that community has helped him and his family.

Luke Waller

A native of Eastern North Carolina, Luke recently graduated from East Carolina University with an MBA in Health Care Management. He was diagnosed with severe hemophilia A as an infant. Over the past several years he has volunteered with the American Red Cross at blood donation drives and community events as a way to give back to his local community much in the way he was helped during childhood and adolescence. Luke has recently joined the National Hemophilia Foundation and HNC with the hope of contributing his experience and expertise, both now and into the future. His particular career interest is in health care operations and management.

Warren Ingram

Warren, 57, has severe hemophilia A, HIV and hepatitis C. He lives with his beautiful wife, Sharon, and their two girls, Torin'ell, 18, and Jasmine, 14. In addition to his two previous terms on the HNC board, Warren has been on the boards of Hemophilia of Georgia; the Committee of Ten Thousand; the Community Collaborative in Mecklenburg County; and has also served on the NHF Multicultural Task Force. Since 2009 Warren has been Director of Patient Advocacy and Care for Advocates Serving and Protecting Foundation, a nonprofit advocating for people with expensive chronic illnesses.

We are very excited to have them on board to bring a great deal of skill and passion for serving the HNC community. With that, however, comes parting with those who have served on the Board with such diligence, talent and heart:

Kathy Register, a long time board member, serving as Treasurer for many years, has shared a wealth of knowledge and experience in many facets over the years. Kathy's big heart and compassion for all will truly be missed on the board.

Guillermo Sanchez dedicated endless hours as a founder of HNC's Latin Union Program. From the beginning, Guillermo recognized the value in developing a program for Spanish-speaking HNC members so they could share and connect. He has left a legacy that is an invaluable resource to the community.

Sally Wright was definitely our go-to on all things insurance and resource related. Her understanding of the inner workings of managing a chronic medical condition was critical to assisting members and chapter staff in navigating through the systems. We are glad she's still only a phone call away!

Leonard Poe led the charge for many years as our VP and Advocacy Chair. His passion, drive and leadership are unmatched in the legislative arena. Over the past few years, Leonard has guided the Advocacy Committee and HNC through an often-complicated process of laws and regulations. We are truly grateful for his expertise and guidance.

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GRIFOLS

Member Spotlight: *Joshua Garrison*

Joshua Garrison is 23 years old and has been a long-term member of HNC, since the 1990s. He is featured in our Member Spotlight this issue, where he shares about his passion for music and the HNC community.

What initially inspired you to make music?

I remember a moment when I was really young and I saw this incredible blues guitarist on TV who just inspired me right then to pick up the guitar, and that was Stevie Ray Vaughan. And shortly after I remember buying my first CD which was Stevie Ray Vaughan And Double Trouble: Greatest Hits 2, and at that point I knew I would be creating music in some way or another for a living.

How has your music impacted or helped you in living with hemophilia?

Music for me has always been a place where I feel like I have no limits. I can pick up a guitar, or sit at a piano and create a song at any given moment, which has given me the ability to be limitless with my creativity. I think its important for anyone living with hemophilia to find a place they can be creative and free, because we have to take control and not let anything stop us from being what we want to be.

What music do you listen to? Are there artists that have an impact in your journey with music?

I listen to a lot of different genres of music. I still listen to some of the great blues players like Jimi Hendrix, Stevie Ray Vaughan, Eric Clapton and BB King. Those guys helped me shape the fundamentals of my guitar playing. I also listen to a lot of newer guys coming up who are taking those influences and making great songs that our generation can relate to like John Mayer and guys like that.

What direction do you plan to take your music in?

Well in the future I plan on bringing a lot of my blues influences into my music and discovering how I can bring that style into a more modern era where you don't really hear that kind of music anymore. I have a lot planned and can't wait to start recording again.

Where do you perform now and where would you like to perform?

Well I will be performing from my home state in NC around the triad area and other major music cities like LA, NYC, ATL and Nashville very soon. I really have no preference on where I play cause I enjoy the intimate venues just as much as larger venues.

If you want to know when and where I'll be performing then just follow me on twitter @JGarrisonMusic for the dates!

How can people get your music?

My EP "River Of Dreams" is available on iTunes, Amazon and many more digital music stores online. You can also stream my songs on Spotify, Jango and other Internet radio stations as well.



Where do you see Hemophilia of North Carolina in 5-10 years?

Hemophilia Of North Carolina is always growing and trying to inspire people with hemophilia. I think it will continue to grow and provide great information to people who may be curious about what they can accomplish living with hemophilia.


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| INDIVIDUAL EDUCATIONAL PLAN ASSISTANCE | |



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Say What? Many Patients Struggling To Learn The Foreign Language Of Health Insurance

As soon as Deb Emerson, a former high school teacher from Oroville, Calif., bought a health plan in January through the state's insurance exchange, she felt overwhelmed.

She couldn't figure out what was covered and what wasn't. Why weren't her anti-depressant medications included? Why did she have to pay \$60 to see a doctor? The insurance jargon - deductible, co-pay, premium, co-insurance - was like a foreign language. What did it mean?

"I have an education and I am not understanding this," said Emerson, 50. "I wonder about people who don't have an education - how baffling this must be for them."

Health officials have spent much of the past year promoting the Affordable Care Act and enrolling people in coverage. Now they need to help consumers understand the basics of health insurance and how to use their policies, health care providers and researchers say.

"Giving somebody an insurance card and not really telling them what that insurance is going to do for them is not going to produce the health outcomes that we all want to see," said Brendan Saloner, a post-doctoral researcher at the University of Pennsylvania. "If the goal is to improve health and lower costs ... it is really important to equip consumers with the education they need."

Patients who don't grasp fundamental health and insurance concepts are less likely to make smart decisions about when and where to seek care, experts said. In fact, people with low "health literacy," as experts put it, are more likely to be hospitalized and use costly emergency rooms, according to the Institute of Medicine.

It's a big problem. About one in 10 people in the U.S. have a proficient level of health literacy, according to an assessment by the U.S. Department of Education - that is, they could understand and use health-related information in daily activities.

And researchers at the USC Schaeffer Center for Health Policy & Economics determined that just weeks before open enrollment began last year for state and federal insurance exchanges, more than 40 percent of Americans couldn't explain a deductible - the amount patients owe for health services before insurance kicks in. The authors found that those likely to benefit most from the health law - uninsured and low-income Americans - had the least awareness.

"There is a huge void," said Bonnie Braun, a health literacy expert and professor at the University of Maryland School of Public Health.

Insurance is often perplexing even to savvy consumers. Acronyms abound: HMOs, PPOs, ACOs. Letters arrive in the mail saying "this is not a bill" yet appear to be just that. Some detail exorbitant prices that have nothing to do with what is actually owed.

Language and cultural barriers add to the confusion. "It's hard to understand even if it is Spanish," said Marisela Sanchez, 50, a new Medi-Cal enrollee from Los Angeles who has diabetes, high blood pressure and high cholesterol. "If it's in English, it's worse."

Community health centers throughout the nation are seeing some of the problems firsthand.

At Eisner Pediatric & Family Health Center in downtown Los Angeles, lead enrollment specialist Martha Vasquez said the vast majority of patients who bought private insurance selected plans with the lowest premiums, not necessarily grasping that those plans came with high deductibles.

Now they are asking why the visits that they consider preventive aren't free and whether hospital visits are included in their plans. They also are uncertain what specialists they can see and what medications are covered.

Jessie Yuan, a physician at the center, said patients have been confused about health insurance for a long time. The new health law "just adds another layer on top of that," she said.

Yuan said she sees it as part of her job to give a brief orientation to new Medi-Cal patients. On a recent morning, she spoke with Oscar Gonzalez, a diabetic patient from Huntington Park, in Spanish. Gonzalez had been switched to Medi-Cal from a free county program for the uninsured.

With Medi-Cal, Yuan told her patient, over-the-counter medications like Tylenol and cough syrup aren't free anymore. He can get a free vision appointment but will have to pay for glasses. It will be easier to get referrals to specialists, but if he needs to change the appointment, he has to do it himself.

And instead of giving him a three-month supply of medications, Yuan explained she would write a refillable prescription that would cover several months.

Gonzalez seemed bewildered.

He didn't even know he had been automatically switched to the Medi-Cal program until Yuan told him. "I knew by the news they were making some changes," he said. "But I don't know all the rules."

The side effects of confusion can be harmful, providers said. Sanchez, the new Medi-Cal recipient from Los Angeles with several chronic conditions, stopped taking two of her regular medications because the doctor didn't write new prescriptions. Sanchez concluded she didn't need them anymore - not realizing that she was supposed to get refills.

"The concept of refill is very difficult for our patients," said Nicole Alton, the Eisner health center's director of pharmacy. "She is just

Continued on page 21

Say What? Many Patients Struggling To Learn The Foreign Language Of Health Insurance *Continued from page 20*

one of hundreds of people who come and don't understand the system."

It's not just low-income patients or those new to insurance who need help navigating the system.

Rob Hoerntlein, 63, had purchased private insurance before but said he is stumped by his new Covered California plan, which took effect in April.

"I still don't understand what the costs or coverage are," said Hoerntlein, who lives near Yosemite and is a licensed real estate agent.

When his wife had some warts burned off, he got a bill for about \$300. Hoerntlein said he was told that he had vision coverage but later told he didn't. The booklet explaining his new health coverage arrived months after signing up for the policy.

To address these problems, efforts are underway across the nation by the government agencies, universities and health plans to help people understand the language of health insurance, what services are covered and how to make the best use of policies. The University of Maryland and the nonprofit Insure the Uninsured Project in

California are among those who have offered workshops or are planning to.

Health insurance exchanges are publishing glossaries of insurance terms. Insurers are holding webinars, sending out welcome kits and trying to make everything "clear, simple and easy to use," said Susan Pisano, spokeswoman for America's Health Insurance Plans. Pisano added that patients will take better care of themselves if they understand their benefits.

Deb Emerson, the Oroville woman who chose a policy through Covered California, said she has spent the last several months reading and asking questions about what is included in her plan and what her financial responsibilities are. She still isn't clear why she paid about \$70 to see a doctor before getting insurance – and \$60 afterward.

Come next month, Emerson expects to become eligible for Medicare and will have to start all over again.

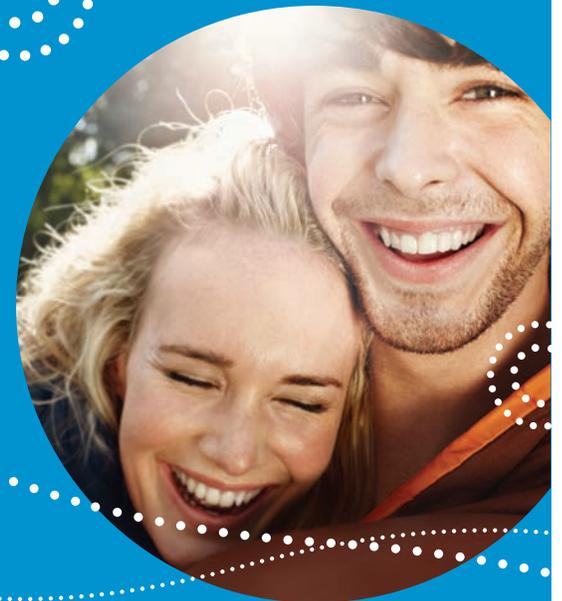
"I am worried it might be more confusing," she said.

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Printed in USA/June 2013

HFA Issue Brief on Specialty Tiers

As the cost of health care continues to rise, more and more health plans are transferring the increased cost of prescription drugs on to patients in the form of cost-sharing arrangements. These cost sharing arrangements include higher premiums, co-payments, deductibles, and coinsurance. Patients living with rare, serious, or chronic conditions are disproportionately impacted by this shift in cost-sharing. A priority concern for these patients is insurers who are implementing “specialty tiers” for prescription drug plans (PDP’s). Background Tiering is a cost-sharing strategy employed by insurers that places drugs into groups called “tiers” based on criteria determined by the insurer. A three-tiered drug formulary is traditionally used by many prescription drug plans. These tiers have fixed co-pays, for example, a \$10 monthly prescription refill for a generic drug. For drugs in specialty tiers however, instead of requiring flat rate co-pays, insurers often require patients to pay a percentage of the cost of a drug. This is known as coinsurance. Specialty tier coinsurance rates can vary from 20% to 50% or more. A specialty tier drug is defined as a category of prescription drugs within a tier in a drug formulary for which a beneficiary’s cost-sharing is greater than tiers for generic drugs, preferred brand drugs, or non-preferred drugs in the prescription drug plan’s formulary.

The most common drug tiering structure used by insurers categorizes drugs in the following way:

- Tier I – Generic Drugs, typically the lowest, flat rate copay
- Tier II – Preferred Drugs, typically a medium, flat rate copay
- Tier III – Non-Preferred Drugs, typically a higher, flat rate copay
- Tier IV, Tier V (Specialty Tier) Unique, high cost drugs, patients charged percentage of cost

In the 2013 survey of Employer Health Benefits, the Kaiser Family Foundation found that 81% of covered workers are in plans with three or more cost-sharing tiers. They also found that coinsurance is the most common form of cost-sharing for the fourth tier.

Impact

Patients living with chronic or life-threatening diseases such as hemophilia are disproportionately impacted by the shift in cost-sharing by insurers who are implementing specialty tiers as part of their drug formularies. Drugs placed in specialty tiers are typically high cost drugs, biologics, and drugs that need special administration and monitoring. Hemophilia drugs are biologics derived from natural sources and can have a higher manufacturing cost than chemically derived formulas. Patients with chronic or life-threatening diseases like hemophilia are reliant upon these expensive medications to stay well.

The ACA currently requires out-of-pocket maximums for health care costs of \$6,350 for individuals and \$12,700 for families. However, for plans that use more than one administrator, the prescription drug plans will not be required to comply with the out-of-pocket maximum requirement until 2015. Even with out-of-pocket limits, a patient using a specialty tier drug could face financial hardship every year because of annual out-of-pocket limit resets.

The cost for medication for adults with hemophilia can range anywhere from \$250,000 to over \$1 million annually. If an individual with hemophilia who uses medication costing \$30,000/month and

has a plan with a 25% coinsurance rate, then each year their January out-of-pocket costs would be the full annual out-of-pocket limit of \$6,350. For most patients, this kind of financial outlay in one month is not feasible.

Numerous studies demonstrate that high out-of-pocket costs for medication lead to decreases in compliance to medical treatment, especially for lower-income groups who are more likely to experience chronic illness. Nonadherence to medication regimens results in \$100 billion spent each year in the US on avoidable hospitalizations. 2 The use of specialty tiers by insurers will continue to escalate this cost even with out-of-pocket limits offering some degree of a safety net for financial catastrophe.

Legislation

Several states such as Delaware, New York, Vermont, and Maine, have enacted legislation that limits or prohibits higher coinsurance rates for drugs in specialty tiers.

Federally, a bill is currently before congress which supports minimizing the cost of specialty tier drugs in commercial health plans. H.R. 460 Patients Access to Treatment Act.

For more information, contact HFA at advocacy@hemophiliafed.org.

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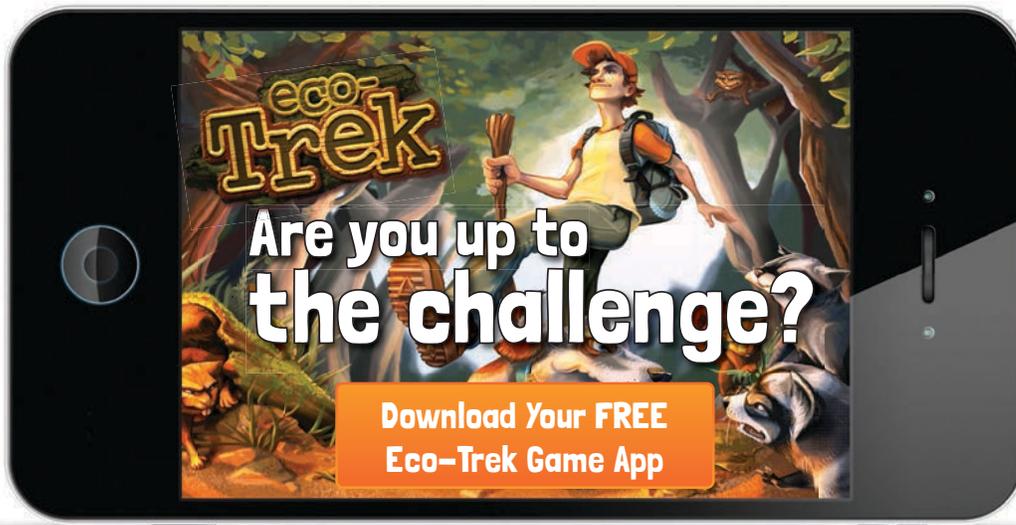
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