

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2016

The Carolina Crew Reach New Heights, Literally!

By: Sue Martin, Hemophilia of SC

The buses from two states rolled into Rock Hill, SC on July 7th, with 30 teens from the North and South Carolina Chapters joining up at Camp Canaan. The annual event is now a favorite; like a family getting together at Christmas and not skipping a beat, as old friends reunite and new ones quickly become engaged.

From the moment the buses arrived it was non-stop interaction. Friday night brought about fun “getting to know you” ice-breakers and late night movies and games. Saturday morning began bright and early playing Bubble Soccer with Kicker Balls and Archery Tag, a favorite for many. Free time for basketball, ping pong, pool time, hanging with friends and a writing project precluded the arrival of Joe Torrey, our facilitator for the Leading Edge Program, “BE PREPARED” sponsored by Pfizer Hemophilia. Joe’s program engaged our teens to get up on their feet, challenged them for life’s experiences, and provided all with knowledge to be prepared and learn to trust others and empower themselves.

Saturday morning brought the biggest challenge of all. The *very high* rope challenge course and zip line. Now

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HNC and HSC Teens, ready to go!

Exciting New Mentoring Program!

For years, our members have been asking about a mentoring program, specifically as part of the HOPE Program for parents or caregivers of young children diagnosed with a bleeding disorder. In the past few months, you may have noticed more talk about making this program a reality. We are excited to now be starting a Mentoring Program for parents!

Hemophilia of North Carolina (HNC) applied for two grants to help support this initiative. First we applied for a grant from the Hemophilia Alliance to start the program. The Hemophilia Alliance is a non-profit organization that works to support Hemophilia Treatment Centers to provide expertise and resources for those affected with bleeding disorders. We also applied to the Colburn-Keenan Foundation Marcy Shulman Memorial Organization Grant.

The Colburn-Keenan Foundation is a charitable organization dedicated to improving the health and well-being of individuals and families affected by chronic illnesses with a main focus on bleeding disorders. These grant awards will help us to be able to provide the necessary resources to implementing a mentoring program as well as providing thorough training to our mentors and mentees.

Our vision is to create a sustainable mentoring program that helps support new parents with an increased knowledge of their child’s bleeding disorder, valuable resources, increased peer-to-peer partnerships, and helps them to become strong and empowered self-advocates for their child. We are starting with a small group of 5-7 mentors and will grow the program as we progress in the future. You may remember receiving a needs assessment survey in your email a couple of months ago. This

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Save The Date

Blood Brotherhood Retreat

Kure Beach, NC
September 23-25, 2016

Latin Union Program

HNC Office in
Morrisville, NC
September 24, 2016

NCNA Conference

Winston-Salem, NC
September 28-29, 2016

HNC Family Retreat

Lake Junaluska, NC
September 30-October 2,
2016

Inhibitor Family Camp

Victory Junction
October 7-9, 2016

Raleigh Walk

Morrisville, NC
October 15, 2016

HNC Yard Sale

Morrisville, NC
October 22, 2016

HNC Blood Brotherhood

Winter Warm-up

Chapel Hill, NC
November 19, 2016

HNC Holiday

Celebration

Jamestown, NC
December 3, 2016

HNC Casino Night

Charlotte, NC
January 28, 2017



*Hemophilia of
North Carolina*

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

MISSION STATEMENT

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

Contact Numbers

Hemophilia of North Carolina

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

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC

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

About This Publication

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

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

UNC Treatment Center

UNC Hemophilia and Thrombosis Center
170 Manning Drive
3rd Floor Physicians Office Building
Campus Box 7016
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

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital 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 Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

Centers for Disease Control & Prevention

1-800-311-3435
www.cdc.gov

Coalition for Hemophilia B

1-212-520-8272
www.coalitionforhemophiliab.org

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.kelley.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

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.

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, a member of the NC Center for Nonprofits.



Exciting New Mentoring Program!

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survey helped us to identify potential mentors as well as those who are looking for support. The mentors selected all had to complete an application which was evaluated to determine whether or not they met the criteria to become a mentor. All are parents who have a child with a bleeding disorder and have been navigating the community for some time.

Recently, we held a training session and are currently working to pair mentors with interested mentees. We are excited to continue moving forward with this program. Each month, the

mentoring pair will meet either in person or over the phone to discuss relevant topics. New parents will have a safe place to share concerns with a person whom they know will be reliable for support in times of need. Over time, we hope to expand the program to include more people and will have ongoing trainings for new mentors and mentees. If you are interested in learning more about the Mentoring Program, contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or call the HNC office.

Your RSVP Matters

At HNC, our mission is to improve the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research, and delivery of supportive programs and services. We are proud of all the ways that we are able to help support our community and the variety of events that we are able to bring to you. We are continuing to add programs and events, many at the request of our members, and this year alone we will have over 50 events including educational dinners, retreats, an annual meeting, social events, and more. All of HNC's educational and support programs do not cost our members anything. We never charge a fee to register or attend an event because we want to be able to provide the education and support to the community, but these events are not free to host.

It is through the generosity of our supporters, donations, fundraisers, and sponsors that we are able to bring these programs to the community. Based upon the number of people who RSVP, we arrange food, reserve space, purchase gas cards, reserve hotel rooms, and more depending on the event. Consider the time and effort that we put into each event. We want our events to be successful and well attended, because we are planning these events for you. There are other organizations in the bleeding disorders community that charge a registration fee for their events in order to curtail the last minute cancellations and no shows. This is not something that we want implement at HNC. We want to be able to continue offering our programs without having to charge fees of any kind.

All too often, we will have someone RSVP for an event and not attend, without calling or emailing to let us know that they won't be able to make it. We recognize that things happen, sometimes last minute. Whether a bleed, illness, or something else that prevents you from making an event that you had already committed to attending, we understand. However, please call or email us to let us know, even if it is last minute! We simply need to know these things so we can rearrange any logistics accordingly and potentially recoup some of the costs when possible. Sometimes we have waiting lists for events as well. If you call to cancel ahead of time, we can contact someone on the waiting list who may be able to attend in your place. Again, we understand that sometimes things come up at the last minute but please give us a call to let us know.

With thanks and appreciation,

HNC Staff

Board Member Spotlight: Rick Clark



Why do I serve? A better question might have been, why don't I serve? When our son was diagnosed with Hemophilia at birth, our family was thrust into a whirlwind situation of having to learn what hemophilia was and how to raise this child while making all the decisions that arise having a child with a bleeding disorder. Since there was no family history of hemophilia we were embarking into an area that we knew NOTHING about!! However, I remember throughout our son's life there have been several people in the HNC family that have poured their advice, love and encouragement into our lives that have given us hope when the road often times felt very narrow and hard.

So, why do I serve? I serve because I care. I serve because I believe I can make a difference. I serve because of having raised a child with severe hemophilia into adulthood. I know how helpless and alone both parents can feel dealing with all of the hemophilia tricks (Thanks Matt!) that arise in your child's life. I serve because I have to believe we can help make life better for the generations that come behind us.

Since I have life experience parenting a child with a bleeding disorder and work experience in many areas of the business world, I feel that I am strategically where I am for a reason. I look forward to what the HNC future will be and how HNC/we can all work together to bring encouragement and better awareness into the lives of the members and outside community as well.

Volunteer Opportunities at HNC

There are many ways to support HNC and give back to the community. One way is through volunteering!

As the number of events and programs grows from year to year, there is always a need for volunteers in order to assure continued success. Members are welcome to help either in the planning stages or during the program/event itself. Some opportunities are listed below. This is your chance to make a difference by sharing your time and talent with the members of HNC. Of course, everyone is very busy so if you have limited time or resources to commit, HNC will work with you to find the best volunteer opportunity to fit your needs.

Ongoing Volunteer Needs at HNC

Office Work and Mailings at the HNC office: Can you spare a few hours each month? Contact the HNC Office to set up a schedule to assist with routine office work or assistance with mailings and other ongoing activities for HNC.

Translation Services: Are you bilingual? HNC routinely needs assistance with interpreting and translation, especially for our Spanish-speaking members.

Special Events Throughout the State: Find out what special events and programs are happening in your region of the state and sign-up as a volunteer! Duties will vary based on the nature of the event.

Attend Programs and Educational Dinners: Help HNC contact and encourage members of the community to get involved with one or more of the many groups for women, men, teens, families and the Latino community.

Annual Walks in Charlotte and Raleigh: Preparing for and at the walks, our specific areas of need would include assistance with planning, organizing, set-up/clean-up, parking, staffing various information and items tables (t-shirts, goodie-bags, doggie-bags, etc.) and more.

If you are interested in being included in our volunteer database, please contact the HNC office.

The Carolina Crew Reach New Heights, Literally!

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the zip line was fun and easy and not that challenging looking. But for some, well, the high ropes course was a different story! What transpired that morning was what we hope for with our teen retreats. Trusting each other, working together and encouraging one another to take moments in life that are difficult and challenging and work through them with support and encouragement. It was beautiful to see those who we thought would never take the challenge, change their mind and challenge themselves and when they unbuckled themselves from the zip-line and it was all over, they gleamed with pride for the accomplishment they achieved. A cozy camp fire with mouthwatering s'mores ended the exciting day.

Sunday morning brought about wrap-up conversations and validations for the objectives and purpose of this retreat, preparing to say our good-byes and the anticipation for next year to be as exciting or even better. Save the Date for next year: **July 6-9, 2017!**



Some icebreakers as teens get to know one another at the Teen Retreat.



Teens participated in many activities at the retreat this year. A game of Bubble Soccer is both fun and funny.

Hemophilia of North and South Carolina wish to thank our 2016 sponsors for their support of this event. We also give a huge shout out and thank you to our staff and volunteer chaperones and to our nurse, Arlette Whitaker, for this event: Charlene Cowell, Sue Martin, Gillian Schultz, Lisa Bordelon, Ric Martin, Shawn Sperry, and Joe Torrey from Gut Monkey!

Please see teen participant contributions in Our Young Voices section, page 16.

Hemophilia of North and South Carolina gratefully acknowledges the pledge of support from the following companies for the 2016 HNC Teen Retreat:

— Program Sponsor —



— Major Sponsors —



HNC Men in the Mountains

June 10-12 in Blowing Rock



This year's Men's Retreat was held at the Blowing Rock Conference Center in Blowing Rock, NC from June 10-12. The weekend was designed to provide helpful programming for adult men who either have a bleeding disorder or have a child with a bleeding disorder. Also, to bring together the men of the community so they can meet one another and find support through mutual experience and understanding.

The retreat began on Friday with an overview of Blood Brotherhood and Dads In Action, two great programs from the Hemophilia Federation of America (HFA). Saturday, Inalex Communications speaker, Haji Sherer, MSW, came back to NC to lead a Men's

Workshop for all participants. After the workshop and some free time, the men regrouped for their dinner cook-out which left everyone full and ready to sit around the campfire to unwind and enjoy each other's company.



Workshop for all participants. After the workshop and some free time, the men regrouped for their dinner cook-out which left everyone full and ready to sit around the campfire to unwind and enjoy each other's company.

After Sunday's breakfast, the group made their way to the New River for a kayak and tubing river float. It was a great relaxing way to end the Men's Retreat.

A Member's Perspective:

John Sakakeeny, long-time HNC member and Blood Brother, attended this year's HNC Men's Retreat and shared some of his experience:

We had fun going down the New River in a kayak and also played pool, because there was a pool table in the lodge. The food at the lodge was very good. You will never go hungry at a Blood Brother event. There is always something to eat or drink and great sites to see around the area. The best part is that we got to see several blood brothers who live in other parts of NC. Can't wait for the next event!

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies and organizations for the 2016 HNC Men's Retreat:

— Workshop Presenters —



— Major Sponsors —



— Supporting Sponsor —



Bring on the BBQ!

June 25 in Morrisville

More than 30 people gathered at the HNC office on June 25 to enjoy some delicious BBQ! Thanks to our grill master Jeff Neal and his wife, Sharon, the day was a complete success. Jeff was managing the smoker before midnight, PULLing an all-nighter so that everyone could enjoy some PULLED pork. Sharon was mixing up different side dishes and preparing the meat, making sure no one would go home hungry. Their grandkids were also a huge help and brought down a bunch of games from HNC's storage area for all to enjoy.

By the afternoon, the office was filled with excitement as members arrived and saw all that was in store for them on a beautiful Saturday. There was no shortage of food or laughs in the office, especially with the friendly cornhole competitions taking place on the patio! Even the local Morrisville police officers came by because they couldn't resist the appetizing smells coming from next door! That was a perfect opportunity for HNC to feed the officers while educating them about bleeding disorders.

The BBQ was a great way to bring the community together in an informal setting. It allowed members the time to realize that they're not alone in navigating their life with bleeding disorders,

whatever their situation may be. A huge thank you to those who came out, and especially to those who helped prepare for the day and cleaned up afterwards. Also, a shout out to the Morrisville Chamber of Commerce, where the HNC office is located, for allowing HNC to use their facilities over the years to host events such as these. Until next time!



Grill Master, Jeff Neal, getting ready for the big day!

Built on strength and experience. Powered by our commitment to you.

With over 60 years of dedicated history to the Hematology and rare disorders communities, Shire has even more resources to bring to the bleeding disorders community. Supported by the passion, commitment and innovation that make a difference, we'll continue to consistently pursue advancements in the treatment of bleeding disorders.

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August 2016 USBS/MG1/16-0496

NHF Annual Meeting Unlike No Other

July 21-23 in Orlando, FL



NHF Annual Meeting welcoming attendees with an international flair.

The National Hemophilia Foundation (NHF) 68th Annual Meeting in Orlando, FL, was unlike any meeting they've hosted before. Nearly 3,000 people came to experience what the NHF Annual Meeting is all about. Taking place from July 21-23, it was infused with a global glimpse of what was in store for attendees who were staying for the World Federation of Hemophilia (WFH) Congress being held immediately after. NHF meeting attendees had the privilege to meet community leaders from all over the world. The work being done by these individuals is remarkable!

HNC members in attendance had a chance to choose from a variety of sessions, including multiple tracks for consumers: families, VWD, women, young adults, adult men, Spanish-speaking, partners, spouses and caregivers. Some of the most popular educational sessions included the exciting results to date on several gene therapy trials and the importance of understanding a patient's half-life. In addition to attending the meeting, Charlene Cowell and Sharon Ingram had opportunities to lead sessions while there.



Charlene Cowell, HNC Executive Director, participates in Panel Discussion at the NHF Annual Meeting.

For the seventh straight year, HNC took home an award symbolizing HNC's support of the World Federation of Hemophilia (WFH). It's an honor to be able to support the WFH through the funds raised by our Walks, and to receive an award that hangs proudly in the HNC office.

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

World Federation of Hemophilia Congress

July 24-28 in Orlando, FL



Thousands welcome World Federation of Hemophilia Congress back to the United States after more than 25 years.

Did you know that this year's International Congress of the World Federation of Hemophilia (WFH) was expected to be the largest in the WFH's history, with more than 6,000 attendees from over 125 countries? The World Federation of Hemophilia (WFH) held their 32nd Congress between July 24-28 in Orlando, FL. This was the first time in more than 25 years that the WFH meeting took place in the United States. The Congress took place immediately after the National Hemophilia Foundation (NHF) Annual Meeting, which allowed some members to experience this making of history.

HNC Staff Perspective

By: Charlene Cowell, HNC Executive Director

WOW! As my first time attending a WFH Congress, I really didn't know what to expect or plan for. The impact of being a part of the WFH Congress is indescribable. I had the opportunity to meet people from all over the world and listen to their stories. It definitely left an everlasting impression. I've never been ignorant of the stark differences

between the US and other countries but most of my knowledge came from reading and third-parties. I realize now that this pales in comparison with hearing someone's story firsthand.

Even before the WFH meeting began I had a chance to meet leaders from all over the world during the NHF Annual Meeting. Sometimes we didn't speak the same language but a smile and hug in the hallway said it all. Going into the WFH Congress, I had already made new friends.

There was such an energizing aura when you walked down the halls or into a meeting room.

I attended sessions to hear from the experts on treatments and learn what's in store for our future. You could feel the hope and optimism from everyone in the room. The future is promising!

Before I knew it my two-day pass had ended and it was time to head back to NC. Everything is still sinking in. I will forever cherish the time spent at my first WFH Congress. This experience brought a new perspective into my journey with HNC and a heightened meaning to the work we do for the bleeding disorders community.



Meeting new friends from around the globe.

Lunch with the Latin Union Group

August 7 in Charlotte

Members who participate in the Latin Union Program joined together on Sunday, August 7 at the Brio Tuscan Grille in Charlotte. In addition to being a charming place to eat, the lunch was a great way to unwind for a few hours with friends. Thanks to Novo Nordisk's speakers and support, the group was able to discuss the importance of advocating within the school system for children with bleeding disorders. Too often, people do not realize the importance of planning for this until a situation occurs and the school is unprepared. By educating the community, everyone can do their part in making sure that school stays a safe environment. After the lunch and some delectable desserts, the group went on their way to enjoy the rest of the weekend!

HNC Brings Educational Dinners to Greenville and Hickory

August 25 in Greenville & September 1 in Hickory

HNC was pleased to offer two educational dinners in August to areas of the state that seldom have programming brought right to their front door-step and often have to travel to participate in these types of educational opportunities.

The first dinner, held at The Seahorse Restaurant in Greenville on August 25, titled *Living with Hemophilia: The Role of Medication Adherence in a Healthy Lifestyle*, was hosted by HNC, the East Carolina University Hemophilia Treatment Center (ECU HTC) and Pfizer Hemophilia. About 30 members from the eastern part of the state came out to learn more about the importance of adherence to treatment and how patients can overcome obstacles while also enjoying a wonderful dinner and the company of fellow HNC members.

The next stop was in Hickory at Bistro 127 on September 1. Members in attendance were able to participate in a program titled, *Living with Hemophilia: Overcoming Challenges*. This dinner was hosted by HNC and Pfizer Hemophilia and focused on coping with chronic illness, communicating with the health care team and other regarding hemophilia, financial considerations of health care through life stages, and the importance of staying physically active with appropriate activities.

HNC would like to thank Pfizer Hemophilia, the ECU HTC and all the members who came out to participate for making these dinners possible.

Want to Know More

about your factor options?



When it comes to your factor therapy, you have choices. And at Biogen, we recognize the importance of continued research as well as supporting the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

To learn more about these options, contact your CoRe Manager:

Tanya Stephenson | Phone: 704.293.6925 | E-mail: Tanya.Stephenson@biogen.com

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Fun and Games: HNC's Family Fun Day

August 21 in Clemmons



It was all fun, games and swimming at HNC's first ever Family Fun Day held at Tanglewood Park and Aquatic Center on Sunday, August 21 in Clemmons.

With early forecasts calling for thunderstorms that afternoon, everyone was nervous about how the day would turn out. Lucky for all, the weatherman missed the mark. Though it was a typical hot and humid NC day, everyone seemed to have a great time.

The picnic pavilion was filled with almost 100 people from across the state for a chance to reconnect with old friends or meet new people while enjoying a picnic lunch, playing games including plinko, corn-hold, ladder golf, crafts and relay races or just sitting and relaxing in the shade. After a brief word from the sponsors, everyone had an opportunity to hear an update from HNC staff about events and programs coming up in the year ahead and the services HNC provides to the community.



Following the picnic, many people were anxious to visit the Aquatic Center to cool down! The Aquatic Center included a splash pad, kiddie pool, large pool including a diving area, waterslides, and lazy river; and everyone appeared to be having a great time! Though the sky looked ominous at times, the thunder and rain held off until about 4:30pm, allowing everyone almost 2 hours to enjoy the Aquatic Center before heading home for some much needed rest!



Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2016 Family Fun Day:

— Picnic Sponsors —

Baxalta DIPLOMAT[®]

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specialty pharmacy

Matrix Health

Pfizer Hemophilia

— Supporting Sponsors —

Colburn-Keenan Foundation

Octapharma



Hattitude for Hemophilia Fundraiser

August 27 in Winston-Salem

The 3rd Annual Hattitude for Hemophilia Luncheon and Fashion Show took place on Saturday, August 27 in Winston-Salem. This unique event was hosted by the Jaden's Jewels and Jaden's Jents (JJ & JJ) team to support their Raleigh Walk team. Jaden's Jewels and Jaden's Jents has been fortunate to have the full support of the St. Stephens Missionary Baptist Church, members who attend the church and other guests.

The venue was utterly gorgeous and the décor was absolutely fabulous! Each table had its own color scheme with individualized centerpieces to match, but still keeping to an overall teapot theme. Even the accessories were coordinated right down to the napkins on the tables! On each napkin roll was a twine that held a teapot charm for each attendee to bring home as a keepsake from their wonderful time!

The name and theme of the event, Hattitude for Hemophilia, has a significant meaning. Women, not limited to those impacted by a bleeding disorder, too often hang their head rather than holding it high. By wearing a hat, it helps to lift their head so that they remember to walk with confidence, as they should. Every woman walked around with such poise – and hattitude!

The fashion show was both informative and filled with entertainment. Models strutted down the runway with grace as they showed off outfits (and hats) for various occasions. There were four scenes to the show: black & white, beach, church, and

the “after 5pm” style. In between the models, the show’s hilarious emcee kept everyone engaged with fashion tips and witty remarks!

Charlene Cowell, HNC Executive Director, had an opportunity to address the attendees to talk about the importance of the Walk

and what it symbolizes for those living with bleeding disorders all across the globe. Even a walk in North Carolina is helping to raise awareness around the world through word of mouth and social networks. Charlene also had a chance to give a heartfelt thank you to the walk team, who from 2012 to 2015 raised an astonishing \$22,000!!

As the fundraiser came to a close, Erica Cook, captain of the Jaden's Jewels and Jaden's Jents team took to the podium for an emotional message. Erica talked about when her daughter was diagnosed with VWD, including the trials and triumphs they've faced and those they continue to face as Jaden gets older. She was especially grateful of the support she felt from the HNC community, medical professionals, and from her church over the years.



Charlene with Erica Cook, Captain of JJ & JJ Team.

HNC sincerely thanks everyone who is involved in the success of Jaden's Jewels and Jaden's Jents team. They have been one of the top fundraising teams in Raleigh since they began fundraising in 2012 and continue to be a role model to other teams. The dedication and determination displayed by team, committee, and church members is inspiring. A special thank you to Gwen Stewart and to the Cook family for always being so organized and creative in their fund- and awareness raising efforts!!

Family Retreat is Coming Up Fast

September 30-October 2 in Lake Junaluska

The Annual Family Retreat is coming up soon, from September 30-October 2. Once again we will be returning to Lake Junaluska Conference and Retreat Center in the NC mountains. The leaves should be beginning to turn making the surrounding scenery beautiful for everyone to enjoy.

The Family Retreat is geared for families who have children twelve and under diagnosed with a bleeding disorder. We focus our programming and education for parents and caregivers who are raising children of this age, and for kids, so they can learn about bleeding disorders and enjoy other activities in an age appropriate way. We also have childcare available for our youngest attendees. This year's retreat will include social time, educational sessions for parents and children, and free time. Accommodations and all meals are provided free of charge to HNC members thanks to the generous support of our sponsors.



Some of the kids from 2015!

Latin Union Members Share Their Stories

September 24 in Morrisville

On September 24, HNC's Latin Union Program will join together to learn about sharing their story while enjoying a catered lunch. Members will participate in an interactive Baxalta Hello Talks Program Sharing Your Story: Advocacy in the Bleeding Disorder Community. Everyone has a story to tell and it is important to be able to share your individual story beyond the bleeding disorders community to raise awareness and build self-confidence. Attendees will learn more about this from presenters Patricia Espinosa-Thomson and Miriam Pimentel. Miriam will share her personal story about having a brother and a son with hemophilia. Be sure to check back to the winter edition of The Concentrate for a review of this program.

9th Annual Raleigh Hemophilia Walk: raising awareness for people with bleeding disorders since 2008

October 15 in Morrisville

Whether you speed walk or stroll, the Hemophilia Walk taking place on October 15 Lake Crabtree Park in Morrisville, NC, is the place to be. HNC members are gearing up for the **9th Annual Raleigh Hemophilia Walk** and hope to see you there!!

This year's fundraising goal is raised from last year's to \$110,000, but there's another important goal for members to reach for and that's to increase the number of walkers. With more walkers, there will be increased awareness for those not familiar with bleeding disorders; so please invite the people you know to walk with you this year. It's not too late to invite friends, family, co-workers, sports teams, church groups or school groups. All are welcome to join in HNC's biggest event of the year!

All Walk donations that you raise will stay right here in North Carolina to help benefit the local community. Hemophilia of North Carolina provides many programs and services throughout the state: the financial assistance program for those in need; many support groups including Blood Brotherhood for men over 18 with a bleeding disorder, SOAR for women affected by a bleeding disorder, HOPE for families with young children with a bleeding disorder & the Latin Union Program; an Annual Meeting of membership that provides opportunities to educate and support one another; retreats for Families, Teens, Women and Men; this newsletter, The Concentrate; and more!

Once at the Walk, there will be fun activities for all, plus Sweet Tomatoes is coming out once again to provide breakfast. Starbucks will be returning this year with some morning pick-me-up! Jecoreiography will get everyone pumped up as they dance along to the beats played by DJ Kevin McVerry, along with the Slap Shot Booth to add to the fun. Miller Motte will provide some much-deserved massages! After the Walk, grab a quick lunch for yourself and a goodie-bag for your four-legged friend and congratulate yourself for a job well-done!

HNC appreciates the support of walkers, volunteers, members and sponsors that contribute to making this event continue to succeed on behalf of all HNC members!



Almuerzo con el Grupo Unión Latina

Los miembros del Grupo Unión Latina se reunieron el Domingo, 7 de Agosto en Brio Tuscan Grille, en Charlotte. Aparte de disfrutar de un lugar encantador para almorzar, la oportunidad fue propicia para compartir por un par de horas con amigos. Gracias al respaldo de Nordisk y sus representantes, el Grupo tuvo la oportunidad de discutir la importancia de difundir y defender dentro del sistema educacional, los problemas de desordenes hemorrágicos en los niños. Demasiado a menudo la gente ignora la importancia de planificar una estrategia, hasta que un evento ocurre y el colegio no esta preparado para enfrentarla.

Educando a la comunidad, cada uno puede contribuir en asegurarse que el colegio sigue siendo un lugar seguro. Luego del almuerzo y de disfrutar de unos postres deliciosos, el Grupo pudo seguir disfrutando del resto del fin de semana!

Caminata anual de la Hemofilia en Raleigh

Ya sea a buen paso, o deambulando la caminata por la Hemofilia que se va a realizar el 15 de Octubre en el Parque Lago Crabtree en Morrisville, NC es el lugar apropiado para estar. Los miembros del HNC se preparan para la novena caminata de la Hemofilia y esperan verlo allí.

Este año la meta de recaudo se ha elevado a \$ 110.000, con un incentivo adicional y es aumentar el número de caminantes. Una mayor cantidad de caminantes permitirá llevar a más personas nuestro mensaje sobre los trastornos hemorrágicos, por lo tanto no dudes en invitar a las personas que conozcas a unirse a nuestra marcha este año. No es demasiado tarde para invitar a amigos, familiares, compañeros de trabajo, equipos deportivos, grupos de iglesias, o grupos escolares. Todos están invitados a participar del evento más importante del año del HMC.

Todas las donaciones que obtengas permanecerán en Carolina del Norte para ayudar a la comunidad local. Hemofilia de Carolina del Norte provee muchos programas y servicios en todo el estado, en el área financiera a aquellos que lo requieren, a los grupos de apoyo incluyendo la Hermandad Sanguínea para Hombres mayores de 18 que padecen algun trastorno de coagulación, SOAR para mujeres afectadas de algun trastorno hemorrágico, HOPE para las familias con niños pequeños con un desorden sanguíneo y el Programa Unión Latina, un programa anual que brinda oportunidades para educarse y apoyarse mutuamente, retiros para las familias, Hombres y Mujeres, esta forma de comunicación, El Concentrado y más.

Una vez en la caminata, podrás participar de actividades divertidas. Sweet Tomatoes va a aportar de nuevo el desayuno. Starbucks regresará este año con algunos refrescos matinales. La coreografía de Jo nos entusiasmará danzando con los ritmos que van a interpretar Kevin McVerry en compañía de el Slap Shop Booth; todos aportando a la alegría general. Miller Motte brindará servicio de un buen merecido masaje. Después de la caminata recibe un almuerzo rápido y una bolsa de delicias para tu mascota. Momento de felicitarse por el buen trabajo realizado.

HNC agradece el apoyo de los caminantes, voluntarios, miembros y patrocinadores que contribuyen a que este evento continúe teniendo éxito en nombre de todos los miembros del HNC.



Unión Latina de Hemophilia: Comparta Su Historia

El 24 de Septiembre el grupo Union Latina de HNC se reunirá a compartir su Historia mientras disfrutan de un almuerzo. Los miembros participaran de un programa interactivo de Baxalta, hoy Shire. Hablemos para contar su historia en el seno de la comunidad de Desordenes Hemorrágicos. Todo el mundo tiene una historia que relatar y es importante ser capaces de compartirla para crear

conciencia y confianza en si mismos. Los asistentes tendrán la oportunidad de conocer más acerca del tema por boca de Patricia Espinosa Thomson y Miriam Pimentel. Miriam compartirá su historia personal acerca de su relación con un hermano y un hijo hemofílico. Asegúrese de revisar el contenido de la edición de invierno de El Concentrado donde encontrará este programa.



La Unión Latina tiene otro evento divertido el 18 de junio en Charlotte. Después de la cena, el grupo está programado para ver el juego de los Charlotte Knights contra los Indios de Indianapolis. Nos gustaría agradecer a Baxalta por su continuo apoyo para los programas de la Unión Latina de HNC.

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SOAR Program Update

HNC's SOAR Program is moving forward with additional programs and events for affected women in the community.

On September 9, HNC held a SOAR dinner at Tribeca Tavern in Cary. This event was put on in partnership with the National Hemophilia Foundation (NHF) and thanks to a grant from the Victory for Women series through NHF. Twelve women attended the dinner and participated in an interactive conversation with Kate Nammacher, NHF Director of Education. The topic was "Managing Stress and Improving Wellness." The women went around the room introducing themselves, and just from the initial introductions it was clear that we all face stressful situations, whether related to our own or loved one's bleeding disorder or in other aspects of our lives. The women learned about how our bodies respond to stressful situations, and through different interactive games, saw how different people find different situations stressful. They then learned about different ways to cope with stress in their lives and the session included a short guided meditation. In addition to a great presentation, the food was delicious including the enormous desserts that followed the meal. Everyone left the dinner feeling full, empowered and with some new techniques and ideas to help deal with stress.

On September 28-29, women from the SOAR group will be exhibiting again at the North Carolina Nurse's Association (NCNA) conference in Winston-Salem. Through these outreach and advocacy efforts, HNC has continued to provide information to the nurses on the front lines. Over the years, nurses and medical professionals come back to the HNC exhibit booth with encouraging news. Since receiving information from HNC at these conferences, they successfully referred a patient or even themselves to be tested and found at that they were affected by a bleeding disorder.



*SOAR members enjoying
 their dessert at the
 SOAR Women's Dinner in Cary.*

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
 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.*

An HNC Program for Girls and Women with Bleeding Disorders

SOAR Program Update continued from page 14

It's time to gear up for the 9th Annual Raleigh Hemophilia Walk on October 15. As in previous years, tutus will be sold at the Walk to benefit the SOAR Program but these tutus do not make themselves! Please help to make the tutus; they are easy to make. Call or email if you are willing to help, and HNC staff and other tutu volunteers will be happy to get you started. Also, think about joining the SOAR team for the walk.

In addition, stay tuned for information about a possible SOAR fundraiser in November or December as well as information on other SOAR events coming up near you!

SOAR is an HNC Program for women and girls who are personally affected by a bleeding disorder. The mission is to improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential. For more information, contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or call the HNC office at (800) 990-5557.



Cayton Elderdice from Walk Team Cayton's Clotters getting tutus ready for the Raleigh Walk.



HAVE YOU SEEN THE SOAR VIDEO?

This is a highlight of local SOAR women that wanted to share their story in hopes that it'll help someone else. *Pass it on!*

1. Go to www.youtube.com.
2. Type in "Hemophilia of North Carolina".
3. Our YouTube channel should be the top result. Click on our logo and it'll take you to all of our videos.
4. Click on the video "Hemophilia of NC – SOAR Program" and enjoy!

Want to help raise awareness by sharing your story? Let us know!

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Teen Retreat Participant Spotlight:

During the event, Hemophilia of North and South Carolina asked teens to write or design something about the retreat and themselves that they would like to share with others. To read about this year's Teen Retreat, go to the cover story that continues on page 4 in the HNC News & Information Section.

Deshauna Baker (NC):

Hi. My name is Deshauna Baker. I am 17 years old. My full name is Deshauna Darling Baker. My birthday is on Valentine's Day. I am a special little girl. My first time going to the Hemophilia teen retreat was a great experience. I got to learn new stuff about Hemophilia and different people that have it. I am really a shy person and quiet. I am going to the 11th grade this year.

Hemophilia of NC is a group of people who have Hemophilia or Von Willebrand's who come together to share their story, form new relationships and help each other when in need. ♥ ♥ ♥

ImageChef.com

Cayton Elderdice (NC)

Cheering on the Youth From NC!

Hemophilia of North Carolina (HNC) will be represented by two teens at the 15th Annual *Gettin' in the Game Junior National Championship (JNC)*, hosted by CSL Behring to be held in Phoenix, Arizona from September 30-October

2. Gavin Griffith will participate in baseball and Jacob Hoernlein will be swimming. This is the first time Gavin and Jacob will be participating in this event and HNC members will be cheering them on throughout the state!

The JNC athletes, who themselves have been diagnosed with bleeding disorders, gather at this annual event which includes clinics to help educate participants and their families about golf, baseball and swimming, and to promote staying active as part of a healthy lifestyle while managing a bleeding disorder.

Each chapter can send two eligible members to participate. Registration for next year's event will take place in Spring 2017 so make sure to check your inbox!



Austin Caldwell, representing HNC at the 2015 JNC, wins Good Sportsmanship Award.

Annual HNC Yard Sale

October 22 in Morrisville

Hemophilia of North Carolina is hosting a Yard Sale at the HNC Office, 260 Town Hall Drive, Morrisville from 8am – 12noon, so clean out your closets, attic or basement, and bring your stuff to Morrisville!

HNC staff and volunteers would love to have you donate items or come by the HNC office to help out the day of the sale.

Suggested items for donation include:

- Small furniture in good condition
- Working appliances
- Dishware/cookware
- Electronics
- Video games
- Books
- Clothes
- Baby stuff
- Artwork
- Home décor
- Shoes
- Music
- Jewelry, purses, accessories
- Holiday decorations



Just give us a call toll-free at 800-990-5557 to coordinate with our staff when you can volunteer or drop off your items on or before Friday, October 21. If you can't make it to Morrisville, why not host a yard sale of your own on the same day and donate the proceeds to HNC? To find out more about this option or if you have any questions about the Yard Sale effort, contact the HNC office at 800-990-5557 or info@hemophilia-nc.org. HNC staff will work with you and advertise your yard sale as part of our statewide event.

Meet Your Hemophilia Community Specialist

Your HCS is a valuable resource to help you manage life with hemophilia. Whether you need information about living with hemophilia, Novo Nordisk products, or support programs, Ajie is there to help. Arrange a one-on-one meeting today!

Ajie Attawia

AJAW@novonordisk.com
331-234-4012

About Ajie

A patient himself, Ajie has been a part of the hemophilia community for most of his life. Originally from Sierra Leone, Africa, he was one of only two people to be diagnosed with hemophilia in his home country during his childhood. Since he's been living in the United States, Ajie has taken part in a large number of volunteer programs. He is proud to be a part of the hemophilia community.



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Warm up with HNC at the Holiday Celebration

December 3 in Jamestown

Save the Date! This year's HNC Holiday Celebration will be held on Saturday, December 3, in the Crystal Garden room at the enchanting Castle McCulloch in Jamestown (near Greensboro). This event welcomes families of all ages to enjoy food, fun, a motivational presentation and a visit from Santa with a gift for all the children in attendance. This is an excellent opportunity to come together and celebrate a great year as a community.

Stay tuned to the HNC website for more details and registration information. Can't wait to spend the holidays with you and yours!



Come Gamble for a Good Cause!

January 28 in Charlotte

The 10th Annual "Hearts for Hemophilia" Casino Night will be on January 28, 2017, so mark your calendar today! Once again, the event will be held at Big Chill in Charlotte! An exciting night is being planned with wonderful food, both silent and live auctions, casino games and music. It's sure to be an entertaining night for all who attend. If you know of a person or business that might want to support the event through an auction or raffle item donation or by becoming an event sponsor, HNC is always looking for new partnerships! To find out more information about the upcoming Casino Night, please call the HNC office.



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HOPE Program Update

- Help
- Opportunity
- Partnership
- Empowerment

Things are really starting to pick up when it comes the HNC's HOPE Program for families! On August 21, we held the first annual Family Fun Day!

Over 90 people attended the program at Tanglewood Park. Guests enjoyed food, games, spent time catching up the Aquatic Center, and learned something new about HNC!

We are also quickly approaching the annual Family Retreat, returning again to Lake Junaluska in the mountains west of Asheville. The retreat is geared specifically towards families who have children twelve and under that are diagnosed with a bleeding disorder. There will be activities and sessions for parents/caregivers and children as well as free time built into the schedule. This popular event is a great opportunity for families to meet or reconnect each year.

Last, but certainly not least, we are moving full steam ahead with our new mentoring initiative. This program is designed to help support parents or caregivers of young children with bleeding

disorders by pairing them with a "seasoned" parent who has been there-done that and will be able to help fellow parents navigate the complicated world of raising a child with a bleeding disorder. For more information about the mentoring program, please contact us.

HOPE stands for Help, Opportunity, Partnership, Empowerment. The mission of HOPE is to improve the quality of life for families of the newly diagnosed through the age of twelve with bleeding disorders, so that they may HOPE to lead a fulfilling life. Together, with a community of other parents, we can support each other so that both parent and child can feel empowered, and not limited by a bleeding disorder. Open to any member of HNC, HOPE programs are geared specifically towards parents with children in this age range. For more information about the HOPE Program, or if you have ideas for programs and events, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or contact the HNC office at (800) 990-5557. You may also check the HNC webpage or Facebook page for updates on upcoming programs and events.



Blood Brotherhood

Blood Brotherhood Update

The Blood Brotherhood program will be hosting the annual beach retreat September 23-25 in beautiful Kure Beach, NC. Men from across the state will enjoy the unique opportunity to learn from one another, share their stories with each other and establish relationships with other blood brothers throughout North Carolina.

Besides the peaceful setting at the beach in early Fall and the chance to connect with friends old and new, one of the other favorite parts of this retreat is the great food! Space at this event is very limited, and priority goes to men that have attended our other Blood Brotherhood events throughout the year. There may still be space, so register today and be sure and attend our events next year!

The Blood Brotherhood Program is celebrating its 10-year anniversary! Thanks to Hemophilia Federation of America (HFA) for presenting this unique program and making lasting friendships for a decade. To celebrate HFA is hosting a Blood Brotherhood Camp Out in Breckenridge, CO on November 10-13. For more info on the Camp Out and to chat with guys from around the country see www.hemophiliafed.org/programs/blood-brotherhood.

The next event for the Blood Brotherhood here in NC is still in the planning stages, so be on the lookout for an announcement of the Blood Brotherhood Winter Warm-up taking place on November 19th in Chapel Hill.

For more information on Blood Brotherhood locally, visit the HNC website www.hemophilia-nc.org, and be on the lookout for announcements about future Blood Brotherhood gatherings and events. All adult men affected by a bleeding disorder are welcome to participate.



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NHF Chapter Recognition Award goes to Charles Register

HNC member Charles Register takes home another award!! This time it is the National Hemophilia Foundation (NHF) Chapter Recognition Award, which annually recognizes the outstanding work of NHF chapter volunteers. Only two individuals took home the award this year and one of them happens to live right here in Durham, NC!

Charles, who lives with severe Factor VIII deficiency, has dedicated the better part of his life to Hemophilia of North Carolina (HNC) as a volunteer. Charles' tasks include website management, logo and publications design, and much, much more! The work Charles does not only saves HNC thousands of dollars each year but it also saves staff from more grey hair!

Other organizations that know of his work continually say, "We need a Charles" and for anyone who knows of all that he does, who wouldn't? Fortunately for HNC, he loves his home in NC as does his beautiful wife and fellow volunteer, Kathy!



Though Charles could not be there to accept his award in person, "Flat Charles" accepted the award on his behalf.

2016 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2016.

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

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2016 SECC Statewide Campaign Kick-Off

HNC was proud to be chosen to participate in this year's State Employees Combined Campaign (SECC) Kick-Off on August 19! Approximately 80 of the SECC charities were in attendance in Downtown Raleigh's Bicentennial Mall, a walkway from the State Capitol to the Legislative Building between the NC Museum of History and the NC Museum of Natural Sciences. This was an excellent opportunity to meet with state employees, discuss the work HNC does throughout the state and ask for their support. Within the two hours of exhibiting, HNC staff met multiple people who were personally impacted by a bleeding disorder, whether it be family members or friends. The event also allowed us to stir up some excitement about the upcoming Raleigh Walk!

SECC is a program offered to North Carolina state employees as a workplace giving campaign. Are you a state employee and interested in making HNC your designated charity? North Carolina state employees can opt to make contributions to an approved charity through a direct payroll deduction providing state employees and retirees an opportunity to choose how to direct their charitable contributions.



HNC Staff setting up for a chance to meet and greet NC's State Employees.



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Providing information to interested state employees, some personally impacted by a bleeding disorder.

Battling the Stress of Living with Chronic Illness

By Robin Madell

Medically Reviewed by Timothy J. Legg, PhD, PMHNP-BC on March 14, 2016

Retrieved from: www.healthline.com

Being diagnosed with a long-term health condition can be frightening and disorienting. Once you move beyond the initial shock of your diagnosis, it's helpful to learn how to cope with the daily stresses of living with your illness.

Everyone is susceptible to the effects of stress. However, living with a long-term condition can make you particularly vulnerable. In addition to the everyday challenges that most people face, chronic illness adds new layers of stressors. For example, you may need to:

- cope with pain or discomfort from your symptoms
- take steps to manage your condition and practice self-care
- adjust to new limitations that your condition puts on your life
- manage increased financial pressures
- cope with feelings of frustration, confusion, or isolation

You can take steps to maximize your quality of life and minimize the challenges of living with a long-term illness. Use the following strategies to help you cope and regain control.

Understand Your Condition

When you're living with a long-term condition, it can be helpful to learn everything you can about your symptoms and treatment options. Ask your doctor specific questions about your condition, but don't stop there. Your local library and patient associations for specific conditions are excellent resources for increasing your knowledge base. You can also find information online, although some sources are more accurate and reliable than others.

Observe your own body too. Pay close attention to what seems to ease your symptoms or make them worse. Use a notebook or calendar to record trends and other insights that might help you manage your symptoms. Share your notes with your doctor so your healthcare team can better understand how your condition affects you.



Try meditation.

Pick up a good book.



Become a Self-Manager

Serving as the day-to-day manager of your own health may help you gain a sense of control and improve your quality of life. Following your recommended treatment plan may help keep your symptoms and stress in check. For example, it's important to take prescribed medications as directed and attend scheduled healthcare appointments. It may help to set up a reminder system in your calendar, daily planner, or smartphone.

Other daily decisions that affect your actions and lifestyle can shape how effectively you circumvent stress. For example, eating nutritious foods and getting enough exercise may help boost your mood, improve your mobility, and ease your symptoms. You should also take steps to manage your attitude, emotions, and relationships.

Manage Emotions

The all-encompassing nature of chronic illness, and the ways it disrupts your life and plans, can elicit a wide range of emotions. These responses may include:

- stress
- grief
- rage
- fear
- depression
- anxiety

Experiment with different ways of managing stress and painful emotions. When you find a technique that works, incorporate it into your daily or weekly routine. Some ideas include:

- exercising
- stretching
- listening to music
- deep breathing
- meditation
- writing in a journal
- cooking
- reading
- spending quality time with family and friends

Battling the Stress of Living with Chronic Illness continued from page 22

It may help to schedule time in your calendar for regular breaks and self-care.

Manage Relationships

Relationship management is also important when you have a chronic condition. You may find that you have limited energy and time available for socializing. Some friends or family members may not understand the challenges you're facing.

Making smart choices about where to focus your time and energy can help you live your best possible life. Focus on the relationships that are most important to you. Let go of relationships that add more stress than support to your life.

Develop Adaptability

Attitude and approach can make a big difference to your quality of life. It's important to develop a healthy acceptance of the lifestyle changes that your condition requires. It also helps to develop confidence in your ability to live within these constraints.

You can take control of your life in ways that make a difference to your everyday experience by approaching your condition with adaptability and confidence. Develop new skills and habits and take a problem-solving approach to figure out what works best for you. You'll be better able to manage challenges as they arise.

The Takeaway

Living with chronic illness can be stressful, but you can take steps to manage your condition and maintain good quality of life. Learn as much as you can about your illness and treatment needs. Be proactive about following your treatment plan and leading a healthy lifestyle. Make time for activities and relationships that leave you feeling happier and supported, while avoiding people and things that stress you out. By adjusting your expectations and practicing self-care, you can make your health and wellbeing a priority.

Article resources

Chronic illness. (2016, January 20). Retrieved from https://my.clevelandclinic.org/health/diseases_conditions/hic_Coping_With_Chronic_Illnesses

Coping with a diagnosis of chronic illness. (2013, August). Retrieved from <http://www.apa.org/helpcenter/chronic-illness.aspx>

Mayo Clinic Staff. (2014, April 8). Stress management. Retrieved from <http://www.mayoclinic.org/healthy-lifestyle/stress-management/basics/stress-basics/hlv-20049495>

Check out these online resources for more information about stress management:

American Psychological Association:
www.apa.org/helpcenter/stress-tips.aspx

Anxiety and Depression Association of America:
www.adaa.org/tips-manage-anxiety-and-stress

Mayo Clinic:
www.mayoclinic.org/healthy-lifestyle/stress-management/basics/stress-basics/hlv-20049495

WebMD:
www.webmd.com/balance/stress-management/stress-management-topic-overview

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Barry Haarde: Wheels for the World Adventure

August 27 in Rocky Mount

HNC members in the eastern part of the state were treated to the rare occurrence of welcoming a community member, Barry Haarde to our state! Barry is biking across the country in order to raise critical funds and awareness of bleeding disorders through the Wheels for the World initiative in support of Save One Life. He has been doing biking fundraisers for the community, on both the national and international levels, for many years but this is the first time he has biked through NC!

As a way to honor the occasion, HNC hosted a welcome dinner in Rocky Mount on August 27 as he was scheduled to stop there for the night along his tour. HNC members listened with interest to Barry's account of his tour starting in Washington State going east followed by the journey southward from New Hampshire to Key West, FL. The highs and lows of his journey, whether it be the terrain or the weather, were fascinating; but the real story is about

Barry Haarde bikes through NC for the first time!



Barry Haarde enjoys a relaxing meal with HNC members in Rocky Mount.

his commitment to the bleeding disorders community through this effort. At the time of the dinner, Barry was just \$3,000 short of his \$50,000 fundraising goal with just two weeks left.

HNC wishes him all the best for a safe and successful completion of this bike tour!

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HNC Advocates Take to Raleigh

By: Nicole Bailey

This past June was my 4th time participating in HNC's Legislative Day. I was able to meet with my senator, Senator Jay Chaudhuri, as well as other members of the House and Senate, including Representative Martin Grier and Representative Duane Hall. Although they already support the legislation that HNC advocates for, it is always so rewarding to be able to continue to provide them with education about the bleeding disorders community and how legislation affects us. I truly believe that when these congressmen hear the stories of the bleeding disorder community, it makes a lasting difference. It is so important for all of us to be our best advocates and reach out to our congressmen about topics that are important to us, especially when it comes to managing bleeding disorders.

This year we were also able to listen in on a House and Senate session. This was the first time I experienced that, and it was very educational to see how our congress in NC operates. This is a great opportunity for anyone looking to gain more knowledge about the process! I would encourage anyone in the community that values their healthcare to attend HNC Legislative Day next year and meet with their congressmen, or better yet, set up an appointment on your own to meet with them in their district while they are not in session!

HNC Legislative Day began with an optional dinner and training session on Monday, June 13 at the Hampton Inn & Suites Raleigh Downtown with overnight accommodations provided to members outside the Raleigh area. On Tuesday, June 14, members met at the HNC booth in the North Carolina Legislative Building, to receive their appointment schedule for the day. Members wore their red ties help start the conversation about supporting people living with bleeding disorders as they met with their legislators and their staff. Legislative Day and the Red Tie Challenge are two initiatives that help raise awareness among the legislators and general public about issues in the bleeding disorders community. If you want more information regarding how to speak to your representatives about issues that relate to you and your experience with bleeding disorders, please contact the HNC Office.



HNC Members at the NC Legislative Building, along with Senator Paul A. Lowe, Jr., wear their red ties to spread awareness about bleeding disorders.



HNC Members observing a House Session in Progress.



HNC members' view of the House Floor.



Getting our ties just right to promote the Red Tie Challenge at HNC Legislative Day.

Every Day is Rare Disease Day and HNC was there!

By: George McCoy

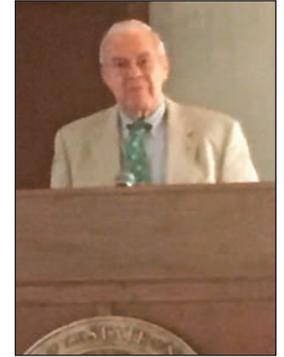
HNC Participated in the “Every Day is Rare Disease Day” event held on Tuesday, June 7, 2016, at the N.C. General Assembly in Raleigh, NC. This event was sponsored by the NC Rare Disease Advisory Council and the NC Rare Disease Coalition to thank the state’s legislators for creating the NC Rare Disease Advisory Council and to demonstrate the strong support for rare disease initiatives in North Carolina. Brenda Nielsen, RN, nurse consultant with the UNC Hemophilia Treatment Center and adjunct assistant professor at the UNC School of Nursing is a member of the NC Rare Disease Advisory Council. HNC is very pleased that people with bleeding disorders are involved with this effort through Ms. Nielsen’s appointment to the Council.

With over 140+ registered, the day attracted significant numbers of rare disease patients and representatives of rare disease advocacy organizations and firms that work in the rare disease community. Foundations, biotech, and pharma companies from across the country that are interested in life sciences of rare diseases participated, as well as researchers and clinicians from UNC-Chapel Hill, Duke University, and NC State University. Staff and volunteers from HNC used the time to network and to learn more about rare disease efforts in NC.

The day was highlighted by remarks presented by individuals who are promoting the state’s leadership in rare disease research and treatment. Tara Britt, Associate Chair of the NC Rare Disease Advisory Council and the NC Rare Disease Institute, welcomed the attendees and thanked them for coming and participating in the event. The Honorable Rufus Edmisten, former NC Attorney General and former NC Secretary of State, introduced the panel of speakers. Mr. Edmisten is a member of the Advisory Council and is also a rare disease survivor. Cecilia Holden,

Chief of Staff for the NC Department of Commerce, addressed the importance of this initiative to the state’s economic development while NC Senator Louis Pate stressed the importance of this legislation on behalf of the one million North Carolinians who have a rare disease. Dr. Bruce Cairns, Chair of the Advisory Council, highlighted the importance of the partnerships among the state and federal governments, advocacy groups, pharma, biotech firms, and academic medical centers. NC Representative Becky Carney, the initial sponsor of the legislation that created the Advisory Council, highlighted the impact of the Council’s work for rare disease patients and their community. She also acknowledged Sharon King’s daughter, Taylor, has Batten disease, which is a rare disease. Mrs. King, who is president of Taylor’s Tale, a member of the Advisory Council and Chair of the NC Rare Disease Coalition, focused on the impact of rare diseases on a society as she shared her personal journey with the attendees. The King family’s commitment to rare disease research and the development of treatments inspired her to propose and advocate for the legislation that created the NC Rare Disease Advisory Council, which is the first of its kind in the nation and was passed unanimously by the NC General Assembly and signed into law by Governor McCrory in August 2015.

HNC will continue to monitor the work of this new Council, and seek to influence its recommendations over time.



Rufus L. Edmisten introducing the panel of speakers.

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Printed in USA 03/16 PP-775-US-0085



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