

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2012

The Next Generation – Youth Leaders for Change

We asked them to bring their voice, energy, insights and experience to become effective advocates for the bleeding disorders community. In September HNC hosted the Youth Leaders for Change workshop for teens ages 14-18 and not only did they come well prepared with these items, but offered so much more. It was a terrific group of young leaders who shared their stories, interests and how they want to make a difference. Throughout the weekend they learned from experts on topics including an overview of current advocacy initiatives, the use of social media, how to share their story, making a difference, effective communications, how to make their 'case' and understanding the legislative process. We talked about some of the issues facing the bleeding disorders community today as well as examples of how effective advocacy has shaped where we are.

Congressman Brad Miller, serving North Carolina's 13th District, stopped by to visit with the group and spoke about what is happening in Washington, DC. He shared his experience on the legislative process, information about health care reform and important tips on how to effect change in addition to answering questions from the group. During the visit, youth leader Austin Caldwell had an opportunity to share his story with Congressman Miller.



Congressman Brad Miller visits our Youth Leaders for Change Workshop

Youth leaders are now working on setting up visits with their legislators and projects to raise awareness and advocate in the community. Guidance in this process will be offered by mentors from HNC advocacy committee members. Kudos to all the great youth leaders who took time out from their busy schedules to

Continued on page 4

Santa Came to Town!

HNC hosted our annual Holiday Celebration on December 3rd at the Speedway Club at the Charlotte Motor Speedway in Concord, NC. Although there was no snow with our celebration this year it certainly didn't dampen the spirits of nearly 200 people who attended the celebration.

It was a terrific venue that was decorated beautifully for the holidays and had a separate room overlooking the impressive racetrack!

Continued on page 4



Santa & His Helper

Inside

Chapter News & Events
Resource Center
On the Health Front
On the National & Legislative Front

Save The Date

HNC Casino Night Fundraiser
January 21, 2012
Durham, NC

Duke Women's Basketball & SOAR Day
January 22, 2012
Durham, NC

SOAR Wine & Design Party
February 5, 2012
Wake Forest, NC

**Teen & Parent Retreat
CEO Program**
February 10-12, 2012
Parkton, NC

**Call to Action Party
Volunteer Leadership Program**
February 25, 2012
Greensboro, NC

**Victory Junction Camp
Spring Sessions**
March 2-4, 2012
March 9-11, 2012

NHF Washington Day's
March 7-9, 2012
Washington, DC

HFA Symposium
March 30-31, 2012
Santa Clara, CA

World Hemophilia Day
April 17, 2012

**HNC 8th Annual Charity
Golf Tournament**
April 20, 2012
The Preserve at Jordan Lake
Chapel Hill, NC



*Hemophilia of
North Carolina*

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

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

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 319-0014

National Hemophilia Foundation Office
(800) 42-HAND1
www.hemophilia.org

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

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

About This Publication

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

We maintain a membership mailing list. However, we never release any personal information without your permission. You may occasionally receive information that is mailed from our office. Your response to these mailings will be of your own choosing and if you would like to "opt out" of all third party mailings, please contact us to remove your name from these mailings.

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

Hemophilia Treatment Centers

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

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

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
http://htc.medicine.duke.edu/

Presbyterian Blume Pediatric Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

American Pain Foundation (APF)
1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
http://painaid.painfoundation.org

American Society of Pediatric Hematology/Oncology
847-275-4716
www.aspho.org

Bleeding Disorders Legal Hotline
1-800-520-6154

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

ClinicalTrials.gov
A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)
1-800-488-2688
www.cott1.org

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

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

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

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

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

World Federation of Hemophilia
514-875-7944
www.wfh.org

VISION STATEMENT Hemophilia of North Carolina's vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.



From the Executive Director

Of all the events we host, I will say that the Holiday Celebration is one of my favorites. Not only is it a great time of year to get together and the moments with the children are priceless, it is also a reminder of how much we were able to accomplish in one year. As part of the celebration, we use the opportunity to highlight our program and services through pictures and discussions. In 2011, HNC hosted 40 programs and services that ranged from small dinners to events with hundreds of people. We expanded our outreach into so many areas through some of our programs including SOAR and the Advocacy Committee. As one of our members, Sharon Ingram, so eloquently describes these opportunities, it is a chance for Each One to Reach One. It is the season to give thanks and we are very grateful for

all the support of our dedicated volunteers, staff, donors, sponsors, other organizations and the Board of Directors who have all provided so much of their time, talent and resources to the community. In particular, I would like to thank all of our members who continue to support what we do by attending events, providing great feedback and helping to continue to educate and involve those who may not be familiar with bleeding disorders. Best wishes to all on a very happy holiday season!

Sincerely,
Sue
 Susan Cowell
 HNC Executive Director

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GRIFOLS

Youth Leaders for Change *continued*



volunteer for this workshop and become the face of the next generation of advocates. Congratulations to Jesse, Matthew, Leslie, Bradley, Sydney, Spencer, Kai, Austin, Shawn, Claire and Emma!

Those that participated will also have the option to attend NHF Washington Day's with the HNC delegation in March where bleeding disorders organizations from around the country come to meet face-to-face with lawmakers and staff who shape national policy.

Our weekend was not all work, no play! Youth leaders, their parents and facilitators all enjoyed a fun evening at the Triangle Rock Club where they used their climbing skills to scale the walls of the largest indoor rock climbing facility in the area!



Our thanks to CSL Behring for their generous support in funding this program through a LEAD Grant opportunity.

Santa Came To Town! *continued*



Guest speakers for the event included Dr. Paulette Bryant from Presbyterian Blume Pediatric Hematology Oncology who shared some great tips for optimizing your health care in the New Year and Karla Zevallos, Spanish Educator for Baxter, who presented information in Spanish to the Latin Union Group participants.

Attendees took time to visit with old friends and meet ones as the children participated in craft activities. Some tasty appetizers were available to feed the crowd as well as a delicious buffet lunch.

We also had an opportunity to share information on another very busy year. HNC has continued to grow, both in size and scope. Membership has continued to increase significantly in all areas and we offered over 40 programs and events in 2011. Highlights from the recent NHF Annual Meeting in Chicago were discussed and our Volunteer of the Year 2011 was announced. Congratulations to George McCoy on this award and our many thanks for all of the time, talent and resources he has provided to HNC over the years!



As part of our advocacy efforts, we also hosted a Youth Leaders for Change workshop in September and recognized those leaders in attendance at the Holiday Celebration for their participation in the program.

Of course, Santa arrived right on time this year along with his elf, who helped distribute gifts to all the children! Each child took time to share their special wish list with Santa and provided some priceless moments! Our special thanks to the Crotts family for always making this such a special day for the children.

We also use this event as a chance to give back to the community and asked our attendees to bring along a gently used or new book that will be donated to the Rotary Club for their annual literacy program. Many thanks to HNC member, Tyronna Hooker, who is also the NC Teacher of the Year, for highlighting the need to improve literacy in the state and suggesting this opportunity to give back. Over 120 books were collected for the donation!

After the celebrations, families were able to ride through Carolina Christmas at the speedway. This is one of the largest holiday light shows in the US and features over 3 million lights.

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

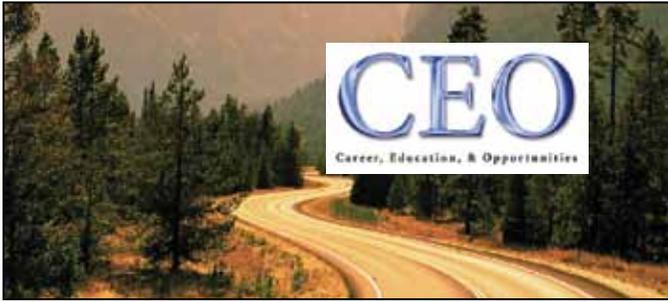
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Save The Date Teen & Parent Retreat

February 10-12, 2012
Rockfish Retreat & Conference Center
Parkton, NC

The Journey Starts Here

You're invited to participate in the CEO Program and the new CEO II module, a totally new way to look at future careers, education, and opportunities. During the day, you'll have a job, a salary, a house, a bank account, as well as a few unexpected surprises and challenges – just like in the real world. It's a fun way to develop your skills and talents while interacting with your peers.

Details:

Dates: February 10-12, 2012

Location: Rockfish Retreat & Conference Center, Parkton, NC

Agenda: Includes both the CEO I for those who have not participated in this program in the past (or those that have and would like to participate again) as well as the new CEO II module.

Activities: Climbing tower, zip line, high ropes course, team building, movie night & campfire

Participants: Teens ages 13-18 and parent(s). Teens may also bring a friend in same age range. Housing will include one room with capacity to hold up to 4 per room.

Registration: Invitations and registration information will be distributed in January.

This program is made available by the support of Baxter and Hemophilia of North Carolina.

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"Playing music helps keep me active." — Frank

"Health insurance can be time-consuming, but I find time to deal with it." — Jay



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Award Winning SOAR Program

HNC's Support, Outreach, Advocacy and Resources (SOAR) program is continuing to make great strides in their mission that is dedicated to improving the quality of life for women and girls with bleeding disorders so they can SOAR to their full potential.

The work of this dedicated team of women and girls was recognized at the recent NHF Annual Meeting with the Award of Distinction in Outreach. The award recognizes chapters with outstanding programs in health education, outreach, communications, and collaboration. Congratulations to all of the SOAR members on this coveted award and recognition of all their hard work.



We are very pleased to announce a generous grant received through the PACT Foundation to continue to support the SOAR program. Funding will provide four educational meetings across the state with school nurses and other school board personnel about bleeding disorders to educate them about girls with bleeding disorders and distribute information packets; hold the first SOAR Advocacy Workshop; host at least two dinners targeting government officials, one being with the NC Women's Legislative Caucus with members

of the National Women's Political Caucus of North Carolina, and a second dinner with key stakeholders; and add five video clips to our collection to help educate and advocate specifically for this population. Our thanks to Baxter BioScience who generously sponsors the PACT State Advocacy Grant Program.

We will be working with Duke University and their Women's Basketball program to support HNC's SOAR Program for women and girls with bleeding disorders (Support, Outreach, Advocacy & Resources). We will be offering free tickets to the Duke vs. Maryland game on Sunday, January 22nd at 3:30pm to those who are attending our Casino Night the evening before on January 21st. So, make plans now for an HNC weekend and save the dates! If you can't make Casino Night, tickets will still be available for purchase to come out and join us for the game. Duke will be highlighting SOAR during the game and we will have an opportunity to share information with the crowd at this popular game of the season. Look for more information soon about these tickets.

The Yellow Boat Play – A Great Success!

In the last edition of The Concentrate, we highlighted HNC member, Caleb Taylor, a theatre major at the *Performing & Visual Arts Academy @ Weaver in Greensboro*. For his senior project, Caleb directed *The Yellow Boat*, (a play about eight year old hemophiliac Benjamin Saar).



Two performances were held on October 21st & 22nd at Weaver Academy and all proceeds from the performances were donated to Hemophilia of North Carolina (HNC). It was an extraordinary performance by the cast and crew that helped share a very powerful message about the dark times in the history of hemophilia. Congratulations to Caleb and everyone involved with the production on a very successful project and our sincere appreciation for selecting HNC as the recipient of the proceeds that total nearly \$1,300.00.

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

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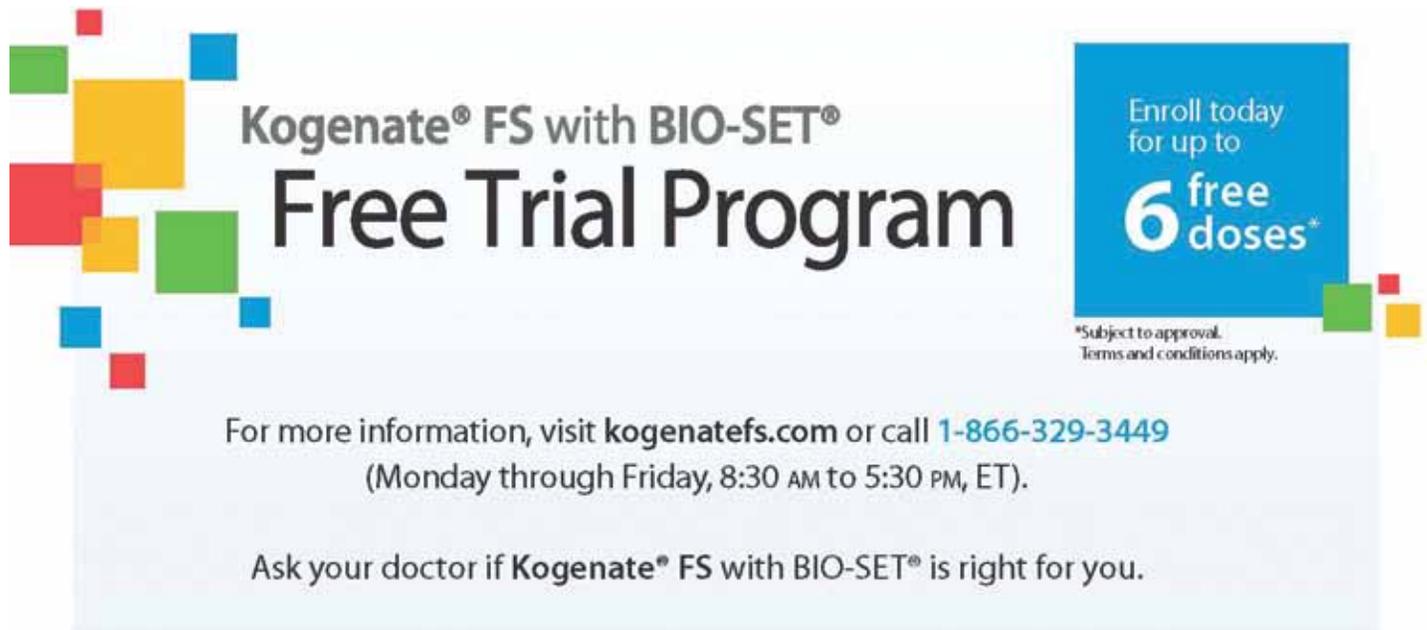
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David Henry • Elaine Hulin • Martha P. Johnson • Mike & Vickie Leonard
Steve & Jane Poe • W. Edward & Joyce Poe • Rachel Sink • Southside Baptist Church

And our thanks for the many donations we received for the 2011 HemophiliaWalk that totaled over \$83,000 and included support from 750 individuals and sponsors. We encourage you to visit our walk site to view these generous donations – www.hemophilia.org/walk



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HNC Volunteer of the Year 2011 Congratulations to George McCoy

Each year, we take a moment to reflect on what we've accomplished and those who helped to make it happen. Our volunteer base grows stronger every year and we had over 200 people this year who shared their time, talents and resources to help bring our members all of the programs and services offered. As always, narrowing that list down to one person who we recognize as our Volunteer of the Year is by far one of the most difficult things to do. One of the things that we are very proud of is our advocacy program and those that work year round on our committee to give a voice to the community. Our volunteer of the year has been involved with HNC for over 30 years and has been instrumental in the passage of many laws and policies that help support the bleeding disorders community. He is the go-to person for any policy or legislative question and his expertise is critical as we move through the health care reform process. He lends his support to many programs of HNC including the NC Advisory Board for Bleeding Disorders, the Blood Brotherhood Program and the Advocacy Committee. A heartfelt congratulations to our 2011 Volunteer of the Year – *George McCoy*.



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Hearts for Hemophilia Casino Night

Saturday, January 21st, 2012 • Bay 7, Durham, NC

We know it is a very busy time of year and getting through the rest of 2011 but we hope you will put our first event of the year on your calendar for 2012 – Hearts for Hemophilia Casino Night.

It will be held this year on Saturday, January 21st at Bay 7 of the American Tobacco Campus in Durham’s Entertainment District. This is a new location for us this year that offers extended hours for our event and a great location that has free parking and plenty to do in the area if you want to make a weekend out of it. The location is near the Durham Performing Arts Center and the Durham Bulls Athletic Park.

Our UNC Jazz Band Quintet will be back to provide entertainment and we’ll have gaming options for all – blackjack, roulette, craps & poker! Our dealers are a fantastic team that makes for a fun night and great teachers if you’re not familiar with the games.

Because we have extended hours, we are offering two ticket options this year. A full night ticket includes hors d’oeuvres, open bar for beer & wine, dinner, dessert, raffle ticket for door prizes and \$20,000 in “fun money” to play the night away from 6:30pm-11:00pm! If you can’t attend the full evening, we are offering a Dessert & Gaming Ticket valid from 8:30pm-11:00pm that includes two drink tickets for beer & wine, dessert, raffle ticket for door prizes and \$10,000 in “fun money”.

As a bonus, each attendee at Casino Night will also receive a free ticket to the Duke Women’s Basketball game on Sunday, January 22nd vs. Maryland (3:30pm). Our SOAR program for girls & women with bleeding disorders will be highlighted at the game as Duke helps to provide support for our efforts. This is a wonderful opportunity to make a getaway weekend for some fun & relaxation after the holidays while supporting a great cause!

Please consider giving a gift of tickets to the evening – a gift that gives back! We’d be happy to provide an accompanying gift card with your tickets that describes the HNC programs & services it is supporting. There are plenty of options not only for individual tickets but also Captain’s Tables with reserved seating for eight and a chance to invite the whole group of family & friends.

Be a Table Captain this year and sell a table of eight by the RSVP date and you’ll receive a free Grand Prize Raffle Ticket, \$5,000 in additional “fun money” (to keep all for yourself or share with your group), and a special gift of appreciation for your support.

We also have many sponsorship opportunities for this event that will fit any size business. The list of sponsorship opportunities is available on the website and we would be happy to provide additional information if needed. Our evening includes a silent and live auction also. We welcome any donated items for this purpose.

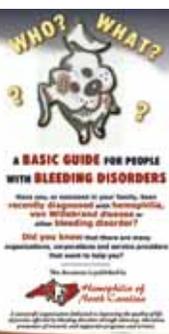
More information on the event, ticket sales and sponsorship opportunities is available on our site at www.hemophilia-nc.org.

Thank you very much for your continued support and have a very Happy New Year!

‘Who-What’ Brochure A Basic Guide for Recently Diagnosed

HNC has developed a brochure to help provide information to those recently diagnosed with a bleeding disorder. The brochure was a product of discussions with families and clinicians who all agreed the time of diagnosis can be very overwhelming to many.

This information provides a basic guide to understanding organizations, service providers, products and commonly used terms.



Brochures will be made available to all new members of HNC as well as existing members, upon request. If you are interested, please contact us at (800) 990-5557 or by email at info@hemophilia-nc.org. Copies will also be distributed through the Hemophilia Treatments Centers and Clinics in North Carolina.

This information will be available on the HNC website at www.hemophilia-nc.org.

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de Unión Latina Hemofilia



Hemophilia Latin Union

El 2011 fue fantástico, tengamos un excelente 2012!

Son tantas las cosas buenas que este año ha traído para el Grupo, que es difícil enumerarlas. Se ofreció el programa de educación en distintas ciudades de Carolina del Norte, en las cuales, los participantes tuvieron la oportunidad de conocer otras familias que enfrentan retos similares causados por algún desorden sanguíneo y de compartir experiencias y consejos que les ayudan a mantener siempre el entusiasmo.

En el 2011 en Grupo ha tenido el honor de tener dos nuevos miembros que han sido clave para su éxito: LaTroya, como Manager del programa; y Nestor, un voluntario con mucho entusiasmo. LaTroya ha inyectado al Grupo toda su experiencia en el trabajo dentro del ámbito de los desordenes sanguíneos y su conocimiento en el funcionamiento de organizaciones sin fines de lucro, lo cual a incrementado los alcances del programa. Por su parte, Nestor y su familia, han dejado toda su energía y talento para alcanzar los objetivos en cada una de las reuniones. Gracias LaTroya y Nestor por llevar el Grupo un paso mas adelante.

Por supuesto que nada de esto hubiera sido posible sin los invitados para dar las platicas educativas, todos ellos nos dieron el conocimiento invaluable acerca de como enfrentar los distintos desordenes sanguíneos y disfrutar de una vida mas alegre.

De seguro tuvimos otros grandes momentos, pero necesitaríamos mas paginas para describirlos. Por lo tanto, el último, y quizás mas grande aplauso, es para todas aquellas familias que mostraron un real compromiso, viajando millas y millas para participar en las reuniones del Grupo de la Unión Latina. Gracias, su presencia nos hace trabajar con mas ganas.

2011 was great, let's have an amazing 2012!

It is hard to enumerate all the good things this year has brought to us. The Group offered its educational program in different cities of North Carolina, where the participants had the opportunity to meet other families facing the same kind of challenges caused by different bleeding disorders and share with each other all the experiences and helpful advice to keep the enthusiasm up.

In 2011 the Group was honored to have two new key members: LaTroya as a Program Manager and Nestor an enthusiastic volunteer. LaTroya has injected to the Group all her experience working in the field of the bleeding disorders and all her knowledge about non-profit organizations, which has already increased the program outreach. Nestor and his family have shared all his energy and talent to achieve the goals in each reunion. Thanks to LaTroya and Nestor for taking the Group to the next level.

And of course none of this could have occurred without all the amazing guest speakers interested in supporting our community. They have given us invaluable knowledge about how to deal with the different bleeding disorders and have an enjoyable and productive life.

For sure there are others great moments that happened this year, but we would need more pages to describe them. So the last, and probably the loudest applause is for all those families that showed a genuine commitment, traveling tons of miles to be at the Latin Union Group meetings. Thanks, your presence makes us work harder.

Esta es una publicación para la Comunidad Latina de Hemofilia de Carolina del Norte y para todos aquellos interesados en crear un lazo de amistad e intercambio con esta Gran Familia Latina.



This is a publication for the entire Latino Community with Hemophilia living in North Carolina and for all those willing to establish a bond of friendship and exchange with this Great Latino Family.

Calendario de Reuniones -Meeting Calendar-

Llámanos para darte información acerca de nuestras reuniones en el 2012.

Visitaremos varias ciudades de Carolina del Norte, No te las pierdas.

Algunos de los eventos del 2012 son:

HNC Reunión Anual –Mayo

Retiro Unión Latina –
Septiembre

Hemophilia Walk-October 20

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O escribenos un email.
union.latina@hemophilia-nc.org

Celebración de Navidad 2011

Las familias latinas comenzaron los festejos de diciembre reunidos en el gran festejo que ofreció Hemophilia of North Carolina para todas sus familias. La tarde comenzó con una interesante charla que nos ayudó a entender la forma en que reaccionamos cuando se presenta un episodio de sangrado: los sentimientos que aparecen en la familia, la forma de actuar de cada uno de los que la integran, ¿Quién es la persona que mantiene la calma y organiza al resto de la familia? Después de

reflexionar acerca de estas preguntas y realizar una actividad en grupo, disfrutamos de una riquísima cena y la visita inesperada de Santa Claus que conversó y entregó un regalo a cada uno de los niños que asistieron a la celebración.

Para nuevos lectores y miembros / For new readers and members

Misión: Hemofilia de Carolina del Norte es una organización no lucrativa, dedicada a mejorar la calidad de vida de personas afectadas por algún desorden sanguíneo, brindándoles apoyo en educación, promoción de estudios de investigación y promoviendo programas y servicios para esta comunidad.

Nuestra Visión: que todas las personas afectadas por algún desorden sanguíneo logran el desarrollo total, sin barreras o limitaciones, hasta que se encuentre una cura.



1, 2, 3... por ti !

¿Tu o alguien de tu familia tiene

hemofilia, o algún otro

Desorden Sanguíneo?

y además hablas español?

Te estamos

buscando!

If you are a **Friend, Social Worker, Physician**, or just happened that **you know someone from Latino America living with a bleeding disorder**, tell them to contact us, we provide with a great educational and networking opportunities in their language: **Spanish**.
Help us now and give the opportunity to change a life!!!

Llámanos hoy!

Consejo Rápido

El conocimiento es la clave para una vida saludable.

En estos días de celebración con la familia y amigos, las personas tendemos a comer más de lo que necesitamos, por lo que en ocasiones, aumentamos de peso considerablemente...

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Comienza el 2012 en buena condición física.



A Fantastic 2011 Hemophilia Walk in NC

At the onset of our walk planning, we set a goal of raising \$65,000 and hosting 1000 participants. We are very excited to announce that through your tremendous support and effort, we reached both goals and far exceeded our fundraising expectations.

Through the hard work of our team captains, fellow walkers, donors and volunteers, the NC Walk raised over \$83,671 in local funds. Together with our national funds and some very generous in-kind donations, the revenue topped \$125,000!



Over 1000 participants joined together on a perfect day of weather at Lake Crabtree County Park for the walk to help raise awareness and support the bleeding disorders community. In all 34 teams gathered in a variety of colorful team tee shirts, many of which were provided through a donation by Grifols, along with hundreds of other individuals for the 5k walk on October 15th. Our activity area was buzzing with walkers, sponsors, vendors & volunteers. We would like to thank our walk partner, Wake County, and the terrific staff at Lake Crabtree County Park for hosting our event free of charge in such a beautiful location.

We also thank our generous sponsors and vendors that helped make the event fun for the whole family with activities that included chair massages by Miller Motte College, coffee and hot chocolate from Starbucks to get us going in the morning, a healthy breakfast provided by Sweet Tomatoes, Whole Foods and Panera Bread, as well as a very generous donation of lunch by Jason's Deli who also provided staff to help serve the masses! Our sponsors at the event also helped provide some great activities that included a Mad Scientist, the Shutterfly Photo Booth, face painting and Good Humor ice cream. We were also well entertained by the Carolina Hurricanes mascot, Stormy, who returned this year along with the Slap Shot Booth where kids were able to take a shot on goal and a chance to win a hockey stick autographed by the team!

The crowd stayed hydrated throughout the day by a generous donation of 1000 bottles of water from Grifols and thirty cases of Gatorade from Pepsi Bottling Ventures.



We were entertained throughout the day by Performance DJ and although they have retired their famous Jambulance, they never missed a beat! They always do a great job keeping the tempo upbeat and lively – many thanks to them for their support for the past four years.

We also did not forget about a favorite four-legged friends who joined us and received their own personal goodie bags provided by Pet Mania, who has generously donated over 100 bags for the past four years, and were dressed up for the occasion with walk logoed bandannas made especially for them!

We were thrilled to have our event emceed again by ABC 11 reporter, Alina Machado, who also joined in our walk around the park. Alina welcomed everyone to the walk and helped kick off our Fun Run, which was new to the walk this year. After some congratulatory announcements, Alina introduced the local dance company, World in Motion who entertained the crowd with their performance and stretch.

The National Hemophilia Foundation VP for Research & Medical Information, Neil Frick, joined us at the NC walk and thanked everyone for their support. There are 20 walks taking place all over the country this year that have raised over \$1.2 million and been host to thousands of walkers who have participated.

In keeping with a tradition we started last year, we recognized three people who showed extraordinary creativity and outstanding efforts in helping with the walk. The King Droplet 2011 award went to Leroy Taylor, our Queen Droplet 2011 was Crystal Hoernlein and the Junior Droplet 2011 went to Zackary Hargett. All of them embodied the spirit of the walk in raising funds and awareness in their local communities.

A very special kudos and thank you to our Walk Chairs this year – the Taylor Family and The Taylor JAG's Team – who did an outstanding job of representing Hemophilia of North Carolina and the walk throughout the year. We also thank our 2011 Host Committee members who helped support the walk in the community.

We would like to acknowledge some of our top fundraisers and teams at this point. Our congratulations and appreciation goes out to –

Our Top Fundraising Teams –

- The Ninth Factor who raised \$5,439
- The Taylor JAGS's who raised \$4,219
- King Droplet's Driplets who raised \$3,640
- Zackary and the Factor VIII's who raised \$3,555
- M.L.D. Team who raised \$2,528

Together, these teams raised nearly \$20,000!

Our Top Individual Fundraisers –

- Tyronna Hooker - \$3,642
- Tiffany Hargett - \$3,455
- Reid Coleman - \$3,155
- Ann Skinner - \$1,588
- Mark & Ashley Davis - \$1,171

Some of Our Largest Teams –

- Grifols
- Biogen Idec Hemophilia
- The Ninth Factor
- The Taylor JAG's
- UNC TarHealers



2011 Hemophilia Walk in NC *continued*



There are so many other teams and individuals who did an extraordinary job of raising funds and registering walkers. This year our corporate support was also very generous and we thank all of the local and national companies who helped make the event such a success. We encourage you to visit the walk website at www.hemophilia.org/walk to view all their outstanding efforts.

The day would not have been a success without the army of volunteers who stayed late at night and arrived early in the morning to help set up and run the event. Everything ran smoothly and a huge thank you to our Volunteer Coordinator, Eli Banks, who recruited dozens of fellow Wolfpack students from NC State University along with Enloe High School volunteers and HNC members who did an outstanding job of jumping right in to help out.

Our photo gallery is available on our Facebook page and we thank our Wolfpack volunteer for taking time to capture the event and Spencer Brisson for filming all the wonderful activities!

The goal of the walk was to raise funds and awareness for those people affected by a bleeding or clotting disorder. Not only did you succeed in accomplishing both of these goals, the energy and enthusiasm from the walk helped to form many new relationships and helped renew old ones that will last for years to come – a very since thank you to everyone for all of your support! It is always a curiosity to know how we did from one

year to the next with a goal to increase participation and awareness. We are very happy to see terrific growth of a 27% increase in locals funds raised and a 33% increase in participants over our 2010 walk. But these numbers don't come close to measuring the success in how many others we were able to reach and share information about bleeding disorders!

We are already looking forward to next year's Hemophilia Walk, scheduled for Saturday, October 20th, 2012 – so SAVE THE DATE! We'll be back in the same place; same time and look forward to seeing you again. Our planning has also begun so if you have some time to share your talents with us and want to get involved, please contact HNC at 800-990-5557 or by email at info@hemophilia-nc.org.

We gratefully acknowledge the support of our National and Local Walk Sponsors. National Presenting Sponsor – Baxter Healthcare, National Pacesetter Sponsor – Bayer, National Official Sponsors – Grifols & Pfizer, National Supporting Sponsor – Biogen Idec Hemophilia. Local Presenting Sponsor – Grifols, Local Gold Sponsors – HPC Intl, MedPro Rx & Novo Nordisk, Local Silver Sponsors – CuraScript, CVS Caremark & Wells Fargo, Local Bronze Sponsors – ASAP Pharmacy, Biogen Idec Hemophilia, Coram, Duke Medicine, Kedrion, Pfizer & Walgreens, Local Supporter Sponsors – Accredo, BioRx, Octapharma & UNC Medical Foundation and Local Kilometer Sponsors – Axiom Therapeutics & Hemophilia First.

Thank you again for all your wonderful support!
Sue Cowell, HNC Executive Director
 & *Anna Chiles, 2011 Walk Event Manager*



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New Foundation Established to Advance Correct Diagnosis, Optimal Treatment of Women & Girls with Blood Disorders

MONTCLAIR, NEW JERSEY, (October 2011) – The Foundation for Women & Girls with Blood Disorders (FWGBD), a non-profit 501(c)3 organization, has been created by leading experts in the areas of blood disorders and women’s health with a unique mission to ensure the correct diagnosis and optimal treatment and management of women and adolescent girls with blood disorders at every life stage. The FWGBD plans to achieve its goal of “Educating providers, changing lives” through a multi-faceted program of healthcare provider education activities.

“Women and girls with blood disorders face unique issues and medical consequences at different stages of life, and we started this innovative organization to address an unmet need for an education resource base in these important areas,” said Andra James, MD, MPH, an Ob-Gyn who is one of the founders and current President of the FWGBD and founder of the Women’s Hemostasis and Thrombosis Clinic at Duke University Medical Center in Durham, NC. “These issues often get buried and fragmented in various sources. The purpose of the Foundation is to create a single site and source where physicians and healthcare providers can go to obtain information.”

Providers can now go to a preview website, www.fwgbd.org, to sign up for news and information and to reserve their place for two inaugural events:

- A December 1 webinar, Women and Bleeding Disorders, will mark the official launch of the Foundation and its full website. The medical expert-led webinar will provide hematologic, obstetric and gynecologic perspectives on this topic.
- A Satellite Symposium will be held on December 9, preceding the 53rd ASH (American Society of Hematology) Annual Meeting and Exposition in San Diego, on the topic of Gynecologic Challenges for Hematologists: Tools for Optimal Management of Women and Adolescent Girls with Blood Disorders.

Both of these education programs are CME-accredited and jointly sponsored by Duke University School of Medicine and the FWGBD.

The FWGBD will focus on raising awareness and understanding for providers who treat such disorders as von Willebrand disease (VWD), other factor deficiencies, hemoglobinopathies, thrombophilia, sickle cell disease (SCD), immune thrombocytopenic purpura (ITP) and anemias.

“We believe that educating key healthcare providers on the challenges women with blood disorders face during each stage of their lives will improve health outcomes for these patients,” said Barbara Konkle, MD, President-elect of the FWGBD, Director of Translational Research at the Puget Sound Blood Center and Professor of Medicine, Division of Hematology at the University of Washington. “We are also committed to translating information and research to ensure that only accurate medical information is used to educate providers and benefit women and adolescent girls with blood disorders.”

In addition to the experts who are its founding board members, the FWGBD has assembled a Medical Advisory Committee of 20 specialists, researchers and educators who are at the top of their respective fields in hematology, thrombosis, sickle cell, obstetrics/gynecology, genetic counseling and emergency medicine. Over the next year, the FWGBD will host symposia and maintain interactive exhibit booths at the meetings of such medical societies as the American Society of Hematology (ASH), the North American Society for Pediatric and

Adolescent Gynecology (NASPAG), the American Society for Pediatric Hematology/Oncology (ASPHO) and the Society for Maternal-Fetal Medicine (SMFM).

Additionally, the Foundation will continue to present CME- and CEU-accredited webinars hosted by leaders in hematology and other fields that treat blood disorders. A second live webinar on the topic of thromboembolism in pregnancy will be scheduled for the first quarter of 2012. Each webinar will be archived on www.fwgbd.org after launch and remain accessible to providers for education and CME credits beyond the live webcast.

“We are excited about launching this Foundation that will focus on preventing the serious consequences across the whole spectrum of blood disorders affecting women and girls,” said Roshni Kulkarni, MD, Founding Board Member, Professor and Division Director of Pediatric and Adolescent Hematology/Oncology at Michigan State University and former Director of the CDC Division of Blood Disorders.

When the full state-of-the-art website is launched on December 1, again at www.fwgbd.org, the Foundation will offer information for healthcare providers, including cutting-edge articles and a professional exchange forum. In addition, an Ask the Expert section will allow healthcare providers to ask specific questions to the FWGBD experts.

“We respect other societies and foundations that are involved with blood disorders and we plan to work with them by having a link to them and inviting them to join us as liaisons and partners,” said Lanetta Jordan, MD, MPH, MSPH, Vice President of the FWGBD, Director of the Department of Sickle Cell Services at Florida Memorial Regional Hospital and Chief Medical Officer for the Sickle Cell Disease Association of America. “At the same time, having our own Foundation will lend credibility to women’s issues – to women’s blood disorders – and to the women and girls they affect, and their healthcare providers.”

About the Foundation for Women & Girls with Blood Disorders

The Foundation for Women & Girls with Blood Disorders (FWGBD) is a non-profit advocacy and education organization dedicated to advancing physician and healthcare provider knowledge of the unique needs and challenges faced by women and adolescent girls with blood disorders. Founded in 2010, the Foundation’s mission is to ensure that all women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage. For more information, please visit www.fwgbd.org.

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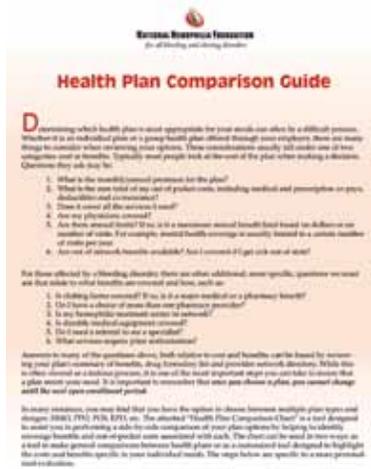
National Program via Hemophilia Federation of America with funding support from CDC & Baxter

Personal Health Insurance Toolkit – NHF Helping Consumers

Understanding and evaluating your health plan options can be a difficult and tedious process. Whether choosing an individual plan or a group plan offered through your employer, there are many things to consider including costs and benefit design. The National Hemophilia Foundation (NHF) has developed the Personal Health Insurance Toolkit to help guide you through this evaluation process.

To obtain a copy of the Personal Health Insurance Toolkit go to: www.hemophilia.org and click on the Health Plan Comparison Guide link in the Helping Consumers area of the site. You may also download a copy from the HNC site (www.hemophilia-nc.org).

NHF also welcomes any feedback you may have regarding the toolkit and this information can be communicated to Michelle Rice, NHF Regional Director for Chapter Services, at MRICE@hemophilia.org.



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New Practice Guidelines for HCV Genotype 1

In October, the American Association for the Study of Liver Diseases (AASLD) approved a new practice guideline for the treatment of genotype 1 chronic hepatitis C virus (HCV) infection. Approximately 70% of people with HCV have genotype 1. The lead author of the guideline was Marc Ghany, MD, from the Liver Diseases Branch of the National Institute of Diabetes and Digestive and Kidney Diseases.

The new guidelines are for use by physicians. They include the addition of one of the two new protease inhibitors – boceprevir and telaprevir – to standard HCV treatment regimens. On May 13, 2011, the FDA approved Merck’s boceprevir under the brand name Victrelis™; May 23rd it approved Vertex Pharmaceutical’s telaprevir under the brand name Incivek™. The first new HCV therapies in ten years, both products represent a new class of drugs called direct-acting antivirals that prevent viral enzymes from replicating.

The current standard of treatment combines weekly injections of pegylated interferon and a daily ribavirin oral pill. However, that regimen is not ideal – nearly 50% of patients do not respond to it. Those who do, often experience debilitating side effects that can last the duration of the treatment – either 24 or 48 weeks.

The new drugs help boost the success of HCV treatment, protecting patients from the potentially severe and life-threatening impact of HCV symptoms, which include liver cancer, cirrhosis, end-stage liver disease and liver failure. Success is measured by patients’ ability to “clear” the virus by achieving a sustained virological response (SVR) for at least six months after completing therapy. Though not technically a cure – HCV is often not completely eradicated from the liver – SVR is still the goal for clinicians. Lowering the viral load to undetectable levels in the bloodstream diminishes the disease’s harmful effects.

The inclusion of a protease inhibitor increases the likelihood that a patient with HCV genotype 1 will reach SVR in up to half the time—24 weeks vs. 48 weeks. The guidelines also note that a blood-based genotype test can be used to predict responses to HCV treatment with pegylated interferon, ribavirin and either of the protease inhibitors.

“Recommendations suggest preferred approaches to the diagnostic, therapeutic and preventive aspects of care,” said Ghany and coauthors. “They are intended to be flexible, in contrast to standards of care, which are inflexible policies to be followed in every case.” That flexibility will be necessary as treatment schedules will vary between patients and side effects will need to be managed carefully. The new drug regimen is not recommended for people with post-transplant HCV or those co-infected with HCV and HIV.

“Hepatologists, gastroenterologists, and others who treat patients with chronic hepatitis C now have the option of two newly approved drugs that directly interfere with the ability of the hepatitis C virus to persist in the patient,” said Gary Davis, MD, chair of AASLD’s special interest group on hepatitis C. “Administration of these drugs is not straight-forward and increases the complexities of patient management. The new AASLD guidelines review how and when to use these agents in the clinic. This timely document should be a great asset in the management of our patients with hepatitis C.”

The new guidelines were published in the October 2011 issue of the journal *Hepatology*.

Source: *Poz.com*,

October 7, 2011; PR Newswire press release dated September 28, 2011

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Printed in USA/March 2011



Research Breakthrough in Gene Therapy for Hemophilia B

Researchers from the United Kingdom (UK) and the U.S. have made a breakthrough in hemophilia gene therapy. In a recently published study, the team reported successfully treating six patients with severe hemophilia B. The lead author of the study was Amit C. Nathwani, MB, ChB, PhD, Department of Hematology, University College London (UCL) Cancer Institute, London.

The UCL investigators used adeno-associated viruses (AAVs) as delivery vehicles, or vectors, to carry the genetic codes that trigger the production of the factor IX (FIX) protein. FIX is deficient in hemophilia B patients. Ideally, AAVs deliver the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses.

Nathwani and his team reported that a single injection of the gene therapy activated the production of small amounts of FIX – enough to allow four of the six subjects to cease treatment with FIX concentrates. The other two patients continued treatment with factor products but needed less frequent infusions. The patients have continued to produce their own FIX for up to 22 months.

Over the last decade, one of the major focuses for researchers has been on developing optimal AAVs. These viruses are often favored because patients have little or no immunity to them. Further, AAVs often target liver cells, which manufacture FIX. One potential drawback is long-term viability as

liver cells do not live indefinitely and are slow to regenerate, which may affect the duration of the therapy.

The AAVs for this study were prepared by a team from the St. Jude Children’s Research Hospital in Memphis, TN. The patients were recruited and treated with the therapy by investigators at UCL. Study co-author Katherine High, MD, and fellow researchers at the Children’s Hospital of Philadelphia, are monitoring the study for any immune reactions.

High’s laboratory has been conducting gene therapy clinical trials for hemophilia for more than a decade. “I think it’s incredibly exciting, and I say that even though these people are my competitors,” said High.

According to Edward G.D. Tuddenham, MB, BS, MD, director of the Hemophilia Center at the Royal Free Hospital in London, 20 additional patients will receive the therapy to help determine the optimal dose of the AAV. The aim is to deliver the highest possible dose while circumventing an unwanted immune response. “We are pretty close to the sweet spot,” explained Tuddenham. “If all goes well, a genetic treatment for hemophilia B could be available for widespread use in a couple of years.”

The study, “Adenovirus-Associated Virus Vector–Mediated Gene Transfer in Hemophilia B,” was published online on December 10, 2011, by The New England Journal of Medicine.

Source: *The New York Times*, December 10, 2011



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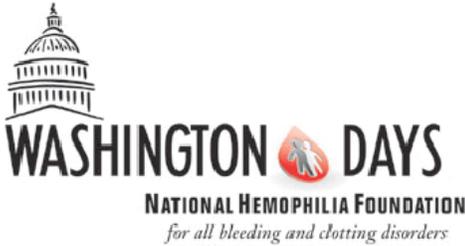
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Medicaid Cuts in NC

Hemophilia of North Carolina has joined a coalition of 20+ other organizations to express concerns about a funding shortfall for Medicaid. We are very aware that many of our members and residents of our state rely on Medicaid for their health care. Through a prepared statement we asked that funding for the identified \$139 million Medicaid shortfall be appropriated so there will be no loss or interruption in services for eligible persons, many of who are among the most vulnerable North Carolinians.

This past week, reports have surfaced that due to conflicting views of how to handle the shortfall in the state Medicaid program, optional services for Medicaid eligible individuals are at risk of being reduced or eliminated and Medicaid provider reimbursement rates may be slashed for both optional and mandatory Medicaid services. Either of these measures will result in decreased access to care for those who need help the most and may force many individuals into more expensive care options which the state has no choice but to pay.

One of the things we have done right in North Carolina is to provide Medicaid services, including optional services such as dental care, physical therapy, mental health services, and in-home care to older adults and people with disabilities, and to ensure that doctors, hospitals, and other medical providers receive a reasonable reimbursement rate so they will continue to see persons on Medicaid.

In summary, it is imperative that the General Assembly provide funding to the Department of Health and Human Services to plug the \$139 million Medicaid shortfall. Medicaid recipients and those whose livelihood relies on Medicaid as a funding source are dependent on this being done immediately.

Please save the date for NHF's 2012 Washington Days, which will be held on March 7-9.

Your participation this year is vital. Given the focus on reducing government expenditures and the continued controversy over health reform and its implementation, it will be critically important for the bleeding disorders community to advocate for policies that benefit us. By telling your story, you put a face on real issues that affect individuals and families dealing with bleeding disorders.

If you are interested in participating as one of the NC delegates, please contact HNC at 800-990-5557 or by email at info@hemophilia-nc.org.

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MEMBERSHIP INFORMATION

The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

For new members, please complete the following application form.

For existing members, we are currently updating our database and would like to make sure we have the most current contact information for you. Please take a moment to fill in the application and check "currently active member – information update".

Please mail completed application to:
Hemophilia of North Carolina
260 Town Hall Dr., Suite A
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Please make checks payable to *Hemophilia of North Carolina*. Your donation may be tax deductible to the extent allowed by law. We are pleased to send you a receipt for your donation.

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Check One

- I am a person with a bleeding disorder.
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- I am a family member of a person with a bleeding disorder.
Relationship _____
Type of bleeding disorder _____
- I am a medical professional.
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