A Trip Around the World!

HNC hosted our 2009 Annual Meeting on Saturday, May 30th where over 100 members were treated to a trip around the world without leaving the state! The theme this year was *Who We Are: A Look at NC and Beyond*. The day began with an informative history of North Carolina and bleeding disorders that was presented by HNC President, Richard Atwood. This was followed with outstanding presentations by Carl Weixler, who shared information about the Hemophilia Federation of America, Ray Stanhope, who spoke on the initiatives and efforts by the National Hemophilia Foundation and Mike Rosenthal, of the World Federation of Hemophilia who spoke about international challenges of finding treatment for all.

Laurie Kelley then spoke with humor and passion about her experiences nationally and internationally on the care & treatment of bleeding disorders. In one hour, we visited the Philippines, Dominican Republic, Romania, India, Zimbabwe & Belize! Members enjoyed Laurie’s fascinating and empowering stories about her visits to these countries and work with Project Share and Save One Life – humanitarian programs set up by Laurie to assist individuals with bleeding disorders around the world.

After lunch, we enjoyed an excellent panel discussion on plasma-derived and recombinant products. Drs. Harold R. Roberts, Alice D. Ma and Albert Farrugia presented information on the different therapies and shared their expertise in this important subject with members in the

Senator Joe Sam Queen Recognized As Hemophilia of North Carolina Legislator of The Year

Dozens of members of Hemophilia of North Carolina met at the State Legislative Building in Raleigh on June 9th to recognize the work of Senator Joe Sam Queen of North Carolina’s 47th Senate District and attend the 2009 HNC Legislative Day.

Senator Queen, working for the people in the hemophilia community since coming to Raleigh in 2002, earned the distinction through his work in health policy and support of understanding and championing the needs of those with a rare chronic illness.

“To advance legislation in a complex policy area, such as Medicaid, allies like Senator Queen are an invaluable resource to Hemophilia patients and their families,” said association member

Continued on page 5

Continued on page 7

Save The Date

Blood Brotherhood Dunn-Benson Dragstrip
July 11, 2009
Benson, NC

Women’s Social The Stocked Pot
July 13, 2009
Winston-Salem, NC

Women’s Social Glazed Expectations
July 21, 2009
Chapel Hill, NC

Kick Off Meeting Hemophilia Walk
August 8, 2009
Morrisville, NC

HNC Family Retreat Hemophilia Walk
August 12-14, 2009
US National Whitewater Center
Pine Knoll Shores, NC

HNC Teen Weekend HNC Family Retreat
September 18-20, 2009
US National Whitewater Center
Charlotte, NC

2009 Hemophilia Walk HNC Family Retreat
October 17, 2009
US National Whitewater Center
Morrisville, NC

NHF Annual Meeting HNC Family Retreat
October 29-31, 2009
San Francisco, CA

Hemophilia of North Carolina
PO Box 70
Cary, NC 27512-0070
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org
Hemophilia of North Carolina is a non-profit organization whose goal is to assist, involve and educate persons affected by bleeding disorders and to educate the medical community and the public about bleeding disorders.

**Contact Numbers**

**Hemophilia of North Carolina**
(800) 990-5557

**Executive Director, Sue Cowell**
(919) 319-0014

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

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

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

**About This Publication**

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

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

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

**Hemophilia Treatment Centers**

**East Carolina University Brody School of Medicine**
PCMH 288 West
Greenville, NC 27858-4354
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**
1712 E. 4th Street
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

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

**The Factor Foundation of America**
1-866-843-3362
www.factorfoundation.org

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

**HIV/HCV Newsletter**
Hemophilia Association of the Capital Area
www.hacacares.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
How fast the year has gone! I can’t believe we are closing out our fiscal year already. It seems like just yesterday that we were in the process of budget planning and deep in discussion about our goals for the year. With two new board members joining us, we have a wonderful team of individuals who are ready to lead us into the next fiscal year. I’m even more excited about what’s to come than what we’ve been able to achieve together over the past twelve months. This last year has definitely been a success for HNC and we’ve been very fortunate to not only sustain but grow during these difficult economic times. Much of that is attributed to the hard work of individuals who share the passion and mission of HNC along with generous support from the national organizations and companies who provide products and services to the community. In twelve short months, we’ve successfully grown our membership, introduced many more programs to the community, met and exceeded our budget projections and most importantly, fulfilled our mission to assist many individuals and families with emergency assistance during this time of need. Thank you for helping to make this all possible!

Sincerely,

Sue Cowell
HNC Executive Director
Perfect Weather, Perfect Golf at the HNC Golf Tournament

What could you not like about beautiful skies, 80+ degree weather, a great golf course and plenty of good people! The 5th Annual HNC Charity Golf Tournament took place at The Preserve at Jordan Lake in Chapel Hill on April 24th. Many of the golfers played hooky from work on this gorgeous Friday (but don’t worry, we won’t tell) and joined their friends for a fun day and great cause.

A team of terrific volunteers was very busy getting everyone checked in, distributing golf gift bags and providing instructions for the day’s events.

A full field of golfers teed off at 12:00 noon with mulligan packages and their Beat the Pro chance tickets in hand. Our special guest player and golf pro, Perry Parker, welcomed the crowd and shared some valuable insights into living with hemophilia and the benefits of supporting the local Chapters for the families and individuals. He then headed off to hole #17 to test the golfers skills at the ever fun, Beat the Pro contest. It is always a challenge to beat Perry and those few that were successful received a divot tool and a chance to win a special prize. We would like to thank our tournament sponsor, CSL Behring, for their continued generous support in sponsoring Perry’s attendance at the event again this year.

Lunch and a delicious dinner was a provided by XU Catering and generously sponsored by Bayer. The non-alcoholic beverages that kept the golfers hydrated during the day were donated by the Women of the Moose at the Lexington Moose Lodge again this year and we are very grateful for their continued generosity and support of HNC.

After dinner, prizes were awarded for teams that placed 1st, 2nd & 3rd along with the Most Honest team.

1st Place – The Cannon Team
Dwayne Cannon, Doug Kaiser, Lance Koegel & Curtis Knight

2nd Place – The Barnes Team
Matt Barnes, Ty Jenks, Kip Harvey & John Blake

3rd Place – The MedPro Rx Team
Andy Clark, Mark Poteet, Stephen Russell & Tom Wells

Most Honest Team
Tom Navaroli, Al Drohan, Anna Thompson & Josh Schlanger

Closest to the Pin
Rick Klusovsky

Longest Drive
Dave Pellowitz

Longest Putt
Sean Halloran

During the tournament, there was a very special entrepreneur, Mr. Nick Carbone and his friends, Bennett & Nick, who set up a lemonade stand on one of the holes with help from their parents. After the tournament, Nick presented HNC with a donation of $54 from the proceeds of the stand – thank you Nick and friends for your generous support!

A Recession Raffle followed the prize presentation where golfers were offered free tickets to win some great raffle prizes including dinner certificates, golf accessories and other items. We offered the free raffle this year in acknowledgement of the tough economic times where everyone can use something free right now and also our appreciation of their support for participating in the tournament.

The live auction of some very notable sports memorabilia closed out the days events. Our favorite auctioneer, Terry Lamb, worked the crowd for some exciting bidding on items that included an autographed team jersey from the Carolina Hurricanes and a Basketball Vault Memorabilia book that was autographed by Coach Roy Williams and Woody Durham.

The night concluded with a thank you from our President, Richard Atwood, to the players and contributors. HNC would like to thank all of our sponsors, gift bag donors, raffle & auction donors, players, volunteers & committee members.
Leonard Poe. Poe presented Senator Queen the 2009 Legislator of the Year award as association members looked on.

“I understand the challenges you face in health care with getting the proper treatment and medicine. I’m pleased to be able to support the hemophilia community and honored to receive this award today,” Senator Queen said.

Members gathered in Raleigh to promote legislative interests including reinstating the funding of a safety net program to assist families of Hemophilia patients with medical and other expenses (Hemophilia Assistance Plan). Additionally, the state’s Medicaid regulations allow patients the freedom to choose medications that work best for them and the group asked legislators to support Senate Bill 324, a bill introduced by Senator Queen, to make permanent the statute that is due to expire on July 1, 2009. The $100,000 cap on specialty drugs in the High Risk Pool (Inclusive Health) was also discussed and members requested support to review this requirement since it makes the plan virtually useless to a person with hemophilia.

HNC was also able to secure space in the lobby of the Legislative Office Building to share information with legislators and their staff throughout the day.
In the Top Ten

Fellow HNC member Janet Hamilton was selected as one of ten national finalists in the Marie Osmond Quilting Challenge 2008/2009. Janet's quilt, Sunbonnet Splendor, is quite a piece of art! The selection of finalists was made by Marie herself and although Janet did not win first place she said it was a real honor to be in the top ten! Janet's quilt was auctioned on Ebay in May and the proceeds donated to the Children’s Miracle Network. Congratulations Janet on a great accomplishment!

SAVE THE DATE

HNC Family Retreat
August 12-14, 2009
Trinity Center, Pine Knoll Shores

We’re excited to be hosting our Family Retreat again this year at the Trinity Center in Pine Knoll Shores. The retreat will feature information and speakers on health & fitness with lots of fun activities! We’ll also be taking a look on how to communicate your needs with your child’s school and develop a plan that works for you. Invitations will be available shortly so watch your email and mailboxes for the latest information & registration!

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

We welcome all Blood Brothers to join us at the Dunn-Benson Dragstrip in Benson, NC on Saturday, July 11th for a fun day out! Lunch and a presentation will be provided followed by tickets to see the Grudge Race and “Gear Jammers” at the Dragstrip. Gates open at 1:00pm. This event is open to all adult men (18 years of age and older) affected by a bleeding disorder and hotel accommodations will be provided on Friday night or Saturday night for those traveling in from outside the region. Bring a fellow brother and come on down! Contact us today at (800) 990-5557 or by email at info@hemophilia-nc.org.

When Only the Best Will Do!

Since 1989, AHF® has set the standard for quality bleeding disorders home care. The AHF pharmacy works exclusively with bleeding disorders...you are our only business. Our specialists will design a care program that is personalized for you. As a result, AHF receives a rating of nearly 100% satisfaction from our clients. Remember, it is your right to choose the very best home care company to meet your family’s needs.

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• Answering your calls with a real person, round the clock
• Negotiating insurance reimbursement
• Arranging home infusion nursing services

Returning a large percentage of all proceeds back to the bleeding disorders community.

For further information contact:
Shirley Moorehead 866-243-4621

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www.AHFinfo.com
31 Moody Road, P.O. Box 985, Enfield, CT 06083 800-243-4621 • AHF@AHFinfo.com
A Trip Around the World! continued

audience. Everyone came away well informed on this topic and confident that they can have an educated discussion on product choice with their health care provider.

Our general business meeting was held and the election of board members took place along with an update of HNC business. New board members Warren Ingram and Scott Andrews were elected for two-year terms. Existing members, Leonard Poe, Kathy Register and Jeannie Adair were elected for new two-year terms.

Susan Cutter of the Penn Comprehensive Hemophilia and Thrombosis Center presented The Financial Factor: Managing the Costs of Hemophilia. The program covered the importance of knowing the cost of your treatment, having a plan of action and valuable insurance information.

The programming for the adults was closed out with a call to action by Leonard Poe, HNC VP Advocacy Chair who encouraged everyone to attend the upcoming HNC Legislative Day and get involved in this very critical year for health care reform.

The children had a great time in the morning with Judy Igelman and her team of volunteers at the Teddy Bear Hospital. They built bears, learned about bleeding disorders and had a great time – thank you Judy and your team of Nurses! In the afternoon, the children worked with a group of educators from Abrakadoodle on art projects from around the world.

Our teen group was a little shy on attendance but NYLI members Shelly Mattson and Patrick Tomlinson did a super job of working with the group and came up with some terrific ideas on future programs. Our thanks to Shelly and Patrick for taking the time out of their busy schedules to attend our meeting and share their experiences with our younger members.

After the meeting, members were invited to attend a baseball game at the Durham Bulls Athletic Park where the Bulls took on the Buffalo Bisons!

Meet Gayle Grossman

We at HNC are pleased to announce that Gayle Grossman has joined us as a summer intern. Many of you may have met her at our recent annual meeting. She will be serving as Program Development Assistant with us until July 30th.

Gayle is completing a Bachelors of Health Education and Promotion from East Carolina University. She has lived in the Raleigh/Cary area since 1999, and is originally from New Jersey. She enjoys learning about hemophilia, and making a difference in the community by promoting awareness of our organization. As program development assistant she will be helping us recruit corporate sponsors for the 2009 Hemophilia Walk.

You may contact Gayle directly by email at gayle.grossman@hemophilia-nc.org. Please join me in welcoming Gayle to HNC.
2009 Friends of HNC

We would like to acknowledge the following individuals who generously donated to HNC during the first quarter of 2009. We extend a sincere thank you to our supporters...many of whom contributed several times during this period.

Donation Made In Loving Memory of Kasey E. Frye
Mr. & Mrs. Donald Anderson
Mr. & Mrs. Eric Boyd
The Cowell Family
Mr. Bill Frye
Mr. & Mrs. Danny Higgins
Mr. & Mrs. William Hill
Mr. & Mrs. Eric Lineberger
Mr. & Mrs. Monroe Poplin
Mrs. Anita Smith
Steve White Motors
Twin City Knitting Company, Inc.

Donation Made in Loving Memory of James “Hut” Hudson Davis
Ms. Elaine Funderbuck

Donation Made in Loving Memory of Lillian Jewel Summey
Ms. Earlene Epperson
Ms. Betty Phillips

Donation Made in Loving Memory of Elva Mae Farmer
Ms. Nancy Combs

Donation Made in Loving Memory of Carl Strohbach
Mr. & Mrs. Richard Adams & Family

Additional Donors
Mr. Nigel Barefoot
Mr. & Mrs. Jeffrey Brill
Ms. Nancy Combs
Mr. & Mrs. Charles Cowell
The Hargett Family
Mr. & Mrs. W. Allen Heafner

Thank You!
Second Annual Benefit Ride In Memory of Kasey E. Frye

By: Richard Atwood

On the day after a tornado touched down in the area, the clouds parted to allow the sun to shine on a group of enthusiastic motorcycle riders in Greenville, NC. This was the second annual memorial ride to remember Kasey Frye that was organized by his good friend, Kacey Wilson. Kasey Frye did not let his hemophilia limit his activities; unfortunately, he was killed in a motorcycle accident in 2008. The proceeds from this event were designated for Hemophilia of North Carolina and for the America Red Cross. Participants were able to donate their blood at the blood mobile bus that was parked at the end of the ride. There was also the opportunity to win raffle prizes and door prizes and to eat a hearty lunch after completing the ride.

The motorcycles had gathered early in the morning at Ron Ayers Motorsports and then, along with a police escort, traveled around Greenville to finally reach J&E Harley Davidson. Joining with friends and extended family, there were many participants from the community who enjoyed riding motorcycles who joined in the event. HNC extends its thanks to Kacey Wilson, his family, and his friends who volunteered their time and energy for this cause that raised awareness for the bleeding disorders community. The success of the Kasey Frye Memorial Benefit Ride indicates that it could be repeated for many years to come.

Hemophilia Walk 2009

October 17th, 2009

Lake Crabtree County Park

Morrisville, NC Update

Teams are forming and sponsors are signing up! The North Carolina Hemophilia Walk 2009 is well underway and the web site is filling with individuals and companies who have begun to fundraise and recruit walkers for this important event. We welcome our early start up teams – the Carrboro Factor Ones, Rob Co’s Finest, Zackary & The Factor 8’s and our walk chair team, Kitty Kat Kathryn!

Remember you can start or join a team, sponsor a walker, volunteer, become a Team Captain, sponsor the walk or organize a group from your local area to participate! The opportunities to help support the walk are endless and will be very rewarding.

Walkers will receive complete support during their scenic walk along the lake with rest stops, traffic control and lots of activities. The park welcomes strollers, pets, wheelchairs and all trails are nicely paved for easy access!

Our goal for the walk in NC this year is $75,000. We are off to a great start with donations and sponsorships totaling $38,270 as of this publishing. We have a ways to go and encourage all of you to get involved to help HNC! Proceeds from this event will help HNC to support and expand many of its programs & services. In addition, it is invaluable in helping to raise awareness about the bleeding disorders community!

Save the date for the official Kick-Off Meeting to be held on August 8th from 3pm-5pm in Morrisville, NC (the location will be announced shortly). All walkers and members are welcome to join this fun event to help in the official kick-off for the Walk.

Please contact us today for more information about setting up a team, sponsorships, making a donation or volunteering!
A Weekend for the Adults

We had a full house at the HNC Adult Retreat in Wilmington on April 18-19th. The weather was terrific and the accommodations very relaxing. In all, 57 people attended the retreat that began on Saturday morning with a welcome breakfast reception and introduction. The reception was followed by a great workshop called “Getting Your Head on Straight” by Inalex Communications, a nonprofit organization that hosts educational sessions on a variety of topics around the country. Our speaker for the workshop was Dr. Ron Potter-Efron, a clinical psychotherapist, author of over 12 books for both professional counselors and the general public and an expert in his field. Topics covered in the workshop included core ideas about healthy thinking, goals to change your way of thinking, challenging negative habits and helping to define simple but healthy thoughts. The sessions were interactive and members had a chance to share their views and ideas with others. Our thanks to Inalex Communications and founder, Joe Caronna, for offering these wonderful workshops to the community.

After the conclusion of the workshop, everyone had a little time to relax and get settled into their rooms at the beautiful Hilton Garden Inn. That evening we met at the Fox & Hound Grille for dinner. A presentation and resource materials were provided on Aging with Hemophilia by Todd Holder of Baxter. We all enjoyed the networking opportunity and getting to know each other a little better.

On Sunday, we had a little R&R time at the waterfront. A trolley provided transportation from the hotel to the Henrietta III for our brunch cruise. The riverboat is the largest in North Carolina and provided a bird’s eye view of the town and a great narration of key points by the captain of the ship.

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

- Baxter
- Bayer
- Bio Rx, Inc
- Inalex Communications
- MedPro Rx, Inc.

We are looking forward to offering more of these retreats in the upcoming year and would welcome your suggestions on other workshops that are offered by Inalex Communications. Feel free to visit their web site at www.inalex.com to view the topics and let us know which ones might be of interest to you.
HNC Latin Union Group Hosts
Cinco de Mayo Celebration at Zoo

The HNC Latin Union Group was host to a wonderful Cinco de Mayo and a World Hemophilia Day celebration at the NC Zoo on May 2nd. HNC member and Hispanic Liaison, Guillermo Sanchez, shared his experience of growing up in Mexico with hemophilia and the challenges he faced. Much of his success and outlook on life can be attributed to the support from his loving wife, Abi who is as active in HNC as her husband! Sue Cowell then presented information on international affairs including the history of World Hemophilia Day, organizations that are helping to improve treatment to people with hemophilia around the world and how each of us can play a role in helping to bring about awareness for the community. Everyone enjoyed great food and fun. The piñata was a big hit with the kids!

Women’s Nights Out!

Join the HNC Women’s group at one of our events. They are open to all women and teen girls so come on out for a fun night of food & conversation! Reserve your space today by calling HNC at 1-800-990-5557 or email info@hemophilia-nc.org

Monday, July 13th
6:30pm – 8:00pm
Creating Crepes
The Stocked Pot
381 Jonestown Road
Winston-Salem, NC  27104
(336) 499-5844
www.thestockedpot.com

Tuesday, July 21st
6:00pm – 7:30pm
Paint Your Own Pottery
Glazed Expectations
1956 Hwy 15-501 South
Chapel Hill, NC  27517
(919) 933-9700
www.glazedexpectations.com

For Teen Eyes Only!

Save the Date for the HNC Teen Weekend
Sept. 18-20, 2009

You’ll be spending the weekend with “Big Dog” in Charlotte and visiting the US National Whitewater Center. Sorry, that’s all the details you’re getting for now but if you miss out on this exciting weekend full of fun, we’ll try not to say we told you so! Sorry parents, you’re not invited to this one. Teens and friends only.
No matter what your health condition, it is important to remain fit so that you are able to manage the normal everyday activities of life. One of the best ways to accomplish this is to submerge your self in water. As a nationally certified aquatic instructor, my advice to those with hemophilia and other bleeding disorders is to get in the water!

Reap the awesome benefits of this great form of exercise!

During the warm weather months we typically have more opportunities to be outside and be more physical, whether it’s gardening, mowing the lawn, or just going for a walk. However, in the winter many of our options for exercise are reduced. Inactivity can lead to stiff joints, weak muscles, and decreased energy. As more indoor swimming pools become available in communities around the country, swimming may be one of the best exercise choices for many people, especially those with bleeding disorders.

In addition to swimming and playing in the water, many indoor pools offer specialized classes. These classes offer wonderful opportunities to keep our joints moving. Though the advantages of being in a structured exercise class are great, one can still substantially benefit by playing, walking, or just relaxing in a pool. Aquatics are great even for non-swimmers!

As with many chronic health disorders, there is going to be some element of wear and tear on specific body parts. Joint problems are common for many people with hemophilia, especially if they have moderate or severe factor deficiencies. Due to the impact and stress put on the joints, strength conditioning programs in gyms may be counter-productive for those with joint problems. By exercising in water, much of the stressful impact on the joints will be avoided. Along with buoyancy, the natural resistive properties of water can help reduce stiffness, decrease pain, as well as improve and maintain joint flexibility. In addition, since the intensity of the exercises is easily adjusted, water exercise is something that virtually everyone can enjoy just by altering the workout to one’s own needs and abilities. Even if all you do is walk in the water, the advantages prevail. Many benefits of water exercise are especially advantageous for the person with a bleeding disorder:

* Maintains or increases range of motion and joint flexibility.
* Inflexible, weak muscles and stiff joints can adversely affect mobility. Since the water supports the weight of the joint, exercises may be more effective in achieving greater range of motion and flexibility than land exercising.
* Reduces pain and muscle spasms.
* People who suffer with pain can greatly benefit from the buoyant nature of water. The deeper one is in the pool the more buoyant they are. With more buoyancy comes less impact on the joints.

Exercising in water may not cure a damaged joint, or halt the progression of arthritis or other joint problems. However, aquatics may facilitate increased strength and flexibility, and improve cardiovascular endurance and improve posture and balance.

* Increases blood circulation.
* Water exercises decrease swelling and counteract the tendency of blood pooling in extremities. Oxygen delivery to the muscles is improved due to the increased blood supply to the muscles.
* Increases cardiovascular endurance.
* Endurance exercises help improve the heart and lungs especially when doing large motor movements. In water, one can achieve this by doing exercises such as jumping jacks, jogging, bicycling, and kicks. These exercises can be done at a variety of intensity levels depending on the person’s ability.
* Improves posture and balance.

A great advantage of exercising in water is the ability to make errors in balance and self-correct oneself without fear of falling onto a hard surface. Abdominal and back muscles are engaged just by standing in the water. This can help improve body alignment and balance outside the pool.

* Promotes relaxation and psychological well-being.

Exercising is one of the simplest and most effective means of stress reduction. Feelings of well-being are created as warm water currents move around the body, acting as a soothing massage.

Exercising in water may not cure a damaged joint, or halt the progression of arthritis or other joint problems. However, aquatics may facilitate increased strength and flexibility, and improve cardiovascular endurance and improve posture and balance. In addition to all these benefits, water exercise is a great stress releaser!

* Wait no longer! See what playing in the water can do for you!

Claire Prudhomme is a Gold Level Master Trainer for WaterArt, a Licensed Massage Therapist, and a Specialized Population Trainer in Champaign, Illinois.

Source: Matrix Health News - Winter 2009, Volume 4, Issue 1
A study published in the journal *Blood* showed that a technique known as “gene transfer” could be used to trigger steady production of activated factor VII (FVIIa) in dogs with hemophilia. Gene transfer typically involves using a non-disease-causing virus (viral vector) to deliver genetic material (transgene) to a person’s cells for therapeutic purposes. The lead investigator of the study was Paris Margaritis, PhD, Division of Hematology, The Children’s Hospital of Philadelphia.

Margaritis and colleagues specifically targeted FVIIa for gene transfer because the protein not only improves hemostasis (the arrest of bleeding) but can also bypass an inhibitor response by the immune system. As a so-called “bypassing agent,” FVIIa can help hemophilia patients avoid an inhibitor by getting around the need to infuse FVIII or FIX without sacrificing effective clotting. This is just one example of the therapies’ potential uses. While much gene therapy research has focused on the production of FVIII and FIX, this study achieved the delivery of a gene-based bypassing agent in a large animal, making it the first successful study of its kind. The breakthrough builds on prior studies, which have shown the approach to be effective and well tolerated in mice.

Results of the current study showed that FVIIa gene transfer was well tolerated by the dogs, that hemostasis improved and that there was no spontaneous bleeding. Potential complications also seem to have been avoided, as there was no evidence of excessive clotting (thrombosis) or destruction of liver tissue (hepatotoxicity). Further, no inhibitor response was reported.

According to the authors, this gene-based bypassing agent approach has a number of potential applications including hemophilia gene therapy, platelet disorders, FVIII deficiency and FVIII/FIX inhibitors.

Success of an experimental therapy in trials with dogs is often considered a stepping stone to eventual human clinical trials. Further studies involving animals and humans, most likely taking years to accomplish, will need to be conducted before this type of therapy could become available.

New York, 2 June 2009 – Because bleeding from the reproductive tract is a naturally occurring event during menstruation and childbirth, women who exhibit menorrhagia, or excessive bleeding after their menstrual cycle, may have underlying diseases that are underdiagnosed. In order to address important issues related to the diagnosis and management of reproductive tract bleeding in women with bleeding disorders, a consensus conference was convened. Results are published in the July 2009 issue of the *American Journal of Obstetrics & Gynecology.*

The goals of the consensus conference were to highlight the problems these women experience and to provide clinical information and recommend strategies to guide practicing obstetricians and gynecologists. Where the international panel of experts in obstetrics, gynecology and hematology reached consensus, recommendations were made.

Von Willebrand Disease (VWD) is the most common inherited bleeding disorder. VWD results from a deficiency in, or a dysfunction of, von Willebrand factor (VWF), a protein necessary for normal platelet adhesion and protection of factor VIII (FVIII) from proteolysis in the circulation. The prevalence of menorrhagia in women with VWD is 74–92%.

Although the majority of women who present with menorrhagia do not have a bleeding disorder, the conference participants identified more than a dozen symptoms that suggest further evaluation, including menorrhagia since puberty, a family history of a bleeding disorder, and personal history of one, but usually several, of the following symptoms: nosebleeds (generally bilateral for more than 10 minutes), more than once in the past year; notable bruising without injury (and with bruises >2 cm in diameter); minor wound bleeding from trivial cuts lasting for more than 5 minutes; or prolonged or excessive bleeding following dental extraction.

A hematologic evaluation of the patient’s platelet number and function and her coagulation factor profile should be assessed in collaboration with a hematologist. Meeting participants also agreed that hematologic evaluations should be repeated to confirm the diagnosis of a bleeding disorder.

Writing in the article with her co-authors, Andra H. James, MD; Peter A. Kouides, MD; Rezan Abdul-Kadir, MD; Mans Edlund, MD, PhD; Augusto B. Federici, MD; Susan Halimeh, MD; Pieter W. Kamphuisen, MD; Barbara A. Konkle, MD; Oscar Martinez-Perez, MD, PhD; Claire McIntock, MD; Flora Peyvandi, MD, PhD; and Rochelle Winikoff, MD. It appears in the *American Journal of Obstetrics & Gynecology,* Volume 201, Issue 1 (July 2009) published by Elsevier.

The article is “Von Willebrand disease and other bleeding disorders in women: consensus on diagnosis and management from an international expert panel” by Andra H. James, MD; Peter A. Kouides, MD; Rezan Abdul-Kadir, MD; Mans Edlund, MD, PhD; Augusto B. Federici, MD; Susan Halimeh, MD; Pieter W. Kamphuisen, MD; Barbara A. Konkle, MD; Oscar Martinez-Perez, MD, PhD; Claire McIntock, MD; Flora Peyvandi, MD, PhD; and Rochelle Winikoff, MD.

Source: [www.elsevier.com/wps/find/authored_newsitem.cws_home/companynews05_01224](http://www.elsevier.com/wps/find/authored_newsitem.cws_home/companynews05_01224)
Hemophilia Federation Adds State Policy Expertise

Washington DC: Hemophilia Federation of America (HFA) is proud to welcome Stephen May in the newly created leadership position of Public Policy, State Affairs. The position was created to ramp up state-level advocacy diligence in response to community concerns of an ever-changing, turbulent healthcare landscape. The position’s responsibility includes pro-active public policy monitoring by collaborating and offering support to HFA member organizations.

Before joining the HFA, May provided advocacy for the bleeding disorder community at the New England Hemophilia Association. His previous experience includes extensive work in organized labor, public policy and state political campaigns.

Mr. May holds a Master’s degree in Social Work from the University of Vermont and an MA in Political Science from the University of Rhode Island, in addition to a Bachelor’s degree in Politics from Ithaca College.

The Hemophilia Federation of America is a national 501 (c) (3) organization consisting of 30 member organizations and numerous individual members who offer assistance and grassroots advocacy on behalf of the bleeding disorders community. Incorporated in 1994, the HFA provides programs and services to improve the quality of life for persons with hemophilia and von Willebrand disease (VWD). For more information call 1-800-230-9797.

Source: Hemophilia Federation of America web site, www.hemophiliafed.org
On Thursday, June 11, 2009, Congresswoman Carolyn McCarthy (D-NY, 4th District) introduced a concurrent resolution to the House of Representatives, supporting the bleeding disorders community in several important ways. The resolution, H.Con. Res. 147, advocates:

- increased research funds for all bleeding disorders
- improved access to treatment centers for all people with bleeding disorders
- greater physician and public education and awareness of bleeding disorders
- enhanced screening and diagnosis rates of undergraduate students and improved treatment of all bleeding disorders

To read the resolution go to THOMAS, the Library of Congress Web site that provides federal legislative information. Both the Hemophilia Federation of America and the National Hemophilia Foundation have voiced strong support for Representative McCarthy’s efforts on behalf of the bleeding disorders community. Further, the resolution has both Democratic and Republican backers.

How you can help

Contact your representative in the US House of Representatives by e-mail, phone or postal mail. To find your representative’s name and contact information, go to: https://writerep.house.gov/writerep/welcome.shtml and enter your nine-digit zip code.

Then URGE YOUR REPRESENTATIVE TO CO-SPONSOR H.Con.Res.147, and ask for a response. A brief statement simply asking your member of Congress to support the bleeding disorders community by signing onto H.Con.Res.147 will work well.

Remember: just a couple dozen constituents can shape a representative’s decisions, so URGE YOUR FAMILY AND FRIENDS TO CALL IN NOW!

Thank you,

Val D. Bias
Chief Executive Officer
National Hemophilia Foundation

Trust the Experience

At CVS Caremark, we’ve been helping families with bleeding disorders for over 30 years. We are committed to helping our patients live well and make better health care decisions.

www.cvscaremark.com/proactive

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Cincinnati, Ohio (June 4, 2009) — On August 5, 2009, two BioRx employees, Jeff Salantai and Eric Hill, will climb Mt. Rainier as part of a national fundraiser called Summit For Someone. The fundraiser benefits at-risk inner city youth who do not have the privilege of experiencing life outside the city. Plus, all proceeds exceeding $8,000 will be donated to “Save One Life.” Save One Life provides financial support, in the form of direct sponsorship, to children and young adults with bleeding disorders in developing countries who do not have the means to acquire their much needed treatments. So Jeff and Eric’s climb will benefit two charitable organizations.

Salantai, who is the Account Manager in Texas, New Mexico and Oklahoma for BioRx, has severe Hemophilia A. He attempted to climb Mt. Rainier two years ago, without achieving the summit. “It turns out the Mountain was much more demanding and taxing than I had expected,” Jeff says. “Therefore, I have decided to pursue it again.”

He challenged Eric Hill, one of the co-founders of BioRx to accompany him on his second attempt.

Eric says, “We will be attempting the 14,410 foot summit in hopes of capturing the peak of one of the largest peaks in the U.S. If successful, we think Jeff may be the first person with hemophilia to summit this mountain.”

They will not have an easy climb by any means. The climb is a technical three-day hike and ice climb at high altitude. It is a physically demanding climb, with less than 40% actually reaching the Summit. Eric and Jeff began training in January for the August 5th event.

If you would like to make a donation to help support Summit For Someone or Save One Life through Jeff and Eric’s climb, go to the Summit For Someone website at www.summitforsomeone.org and click on the “Donate” button, located on the left navigation bar. Then click on “Donate to Climber” and search for “Jeff Salantai”. Follow the instructions to make a secured donation via a credit card. Your gift is a tax deductible donation. Or, if you prefer, you may donate by writing a check to Save One Life and mention “Jeff Salantai and Eric Hill’s Climb” on the memo line. Mail the check to: Save One Life, Inc., PO Box 922, Byfield, MA 01922.

Source: Bio Rx news release, June 4, 2009
CSL Limited and Talecris Biotherapeutics Agree to Terminate Merger Agreement

*Melbourne, Australia — 08 June 2009*

CSL Limited (ASX: CSL) and Talecris Biotherapeutics, Inc. announced today that they have mutually agreed to terminate their merger agreement, announced on August 12, 2008, under which CSL agreed to acquire Talecris for US$3.1 billion in cash.

Dr. Brian McNamee, CEO and Managing Director of CSL Limited, said, “We are disappointed that the U.S. Federal Trade Commission (FTC) resolved to block the transaction. As we have previously stated we fundamentally disagree with the FTC case and matters included in their complaint. Although we continue to believe in the many customer benefits and significant financial synergies that supported the transaction, CSL’s Board of Directors did not believe that entering into a protracted litigation process with the FTC, with its inherent risks, substantial costs, and lengthy distraction of CSL management and staff from planning and running our businesses would be in the best interests of our stakeholders.”

Dr. McNamee continued, “While we regret that the transaction cannot be completed, CSL remains a well positioned global biopharmaceutical business and will continue to expand on its core strengths. We have consistently produced year-on-year growth for our shareholders and we are confident in the continued value and growth potential of our stand-alone business. We continue to have great respect for Talecris and wish them well in the future.”

Lawrence D. Stern, Talecris’ Chairman and Chief Executive Officer, said, “After discussions with CSL, we have mutually agreed that litigation regarding the antitrust issue was not the path forward. Based on a careful analysis of the situation and all alternatives available, we believe that termination of the merger agreement is in the best interest of all parties. We are disappointed that patients will not benefit from the efficiencies we saw in the proposed combination. Talecris continues to focus on its patient community and customers, and on building and realizing value for its employees and owners. Through the process, we developed an even greater appreciation for CSL’s competencies, professionalism and integrity, and we wish Brian and his team well in their future endeavors.”

Both parties will fulfill their obligations for termination contained in the merger agreement. As part of the agreement, CSL will pay Talecris a US$75 million break fee, and the plasma supply contract the parties entered into in connection with the merger agreement will remain in effect.

CSL and Talecris remain highly committed to their respective customers and patient communities.

Source: www.cslbehring.com
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 applications to:
Hemophilia of North Carolina
P.O. Box 70
Cary, NC 27512-0070

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.

Membership Application

Name:__________________________________________________________________________________
Address:_________________________________________________________________________________
City:___________________________________________  State:_____________  Zip:__________________
Home Phone:____________________________________ Cell Phone:________________________________
Email:___________________________________________________________________________________

Check One

____ I am a person with a bleeding disorder.
   Type ______ (ie: VII, IX,VWD)
____ I am a family member of a person with a bleeding disorder
   Relationship _________________
   Type of bleeding disorder _____________________________
____ I am a medical professional
____ I am an interested person
____ I am a currently an active member – information update

Annual membership fees, while not mandatory, are at the following suggested rates:
Individual Member $10 Supporter $100
Family Membership $25 Patron $200
Contributor $50 Benefactor $500

Calendar of Events
We have a busy year planned and thought we would share some of these HNC dates in advance so that you can mark your calendars. We anticipate adding more programs as we continue to plan our event. As those dates become available, we will let you know.

Blood Brotherhood – July 11th
Women’s Nights Out – July 13th & July 21st
Kickoff Meeting – Hemophilia Walk – August 8th
Family Retreat – August 12th-14th
Teen Retreat – September 18th-20th
2009 Hemophilia Walk – October 17th
NHF Annual Meeting – October 29th-31st
San Francisco, CA
HNC Holiday Celebration – December 5th
“Hearts for Hemophilia” Casino Night – January 23rd, 2010

The best resource for the latest information, registration and event updates is to visit the web site at www.hemophilia-nc.org.
SAVE THE DATE
Saturday, October 17th, 2009
Lake Crabtree County Park ♦ Morrisville, NC

Sign up today and make a difference!

www.hemophilia.org/walk