



The Bleeding Times

Serving the Bleeding Disorder Community

Spring / Summer Edition 2010

www.nyhemophilia.org

New York City Hemophilia Chapter

New York City Hemophilia Chapter

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A message from your 2010 NYC Hemophilia Walk Co-Chair, Shari Bender

Hemophilia is important to me. My teenage daughter, Rose, has severe FVIII deficiency. If you are reading this, bleeding disorders mean something in your life too. Perhaps your son, your husband, your sister, your patient, a dear friend, or even yourself, is living with a bleeding disorder. NYC Hemophilia Walk is an opportunity for the bleeding disorder community, and the community at large- friends, family, neighbors, even pets- to come together and show support for those who suffer from hemophilia and its related complications.



Hemophilia is a serious disease, but Hemophilia Walk is serious fun! You'll enjoy entertainment, rainbow bagels and ice cream pops with the unparalleled camaraderie of the hemophilia community, all in the beautiful backdrop of New York City's Riverside Park. There's a one-mile route for even the littlest walkers, and a 5K route for those who want to take things a step further (pun intended!).

Raising critical funds for **education, advocacy, better treatment** and of course, **research for a cure** has never been easier or more fun! Visit our website www.hemophilia.org/walk (select New York from the drop down menu) to start forming your Teams and begin fundraising *today*. Get creative with your Team names (my team name...Team AWESOME!).

With your help, 2010 NYC Hemophilia Walk on June 6th is sure to be our best walk yet!

Feel free to email or Facebook me directly or contact our Walk Manager, Jeri Krassner/jeri.krassner@nyhemophilia.org with any questions or ideas.

See you Sunday, June 6th!



RESEARCH NEWS

Benefits of Prophylaxis in Children with Hemophilia B

The results of a study published last month in the journal *Haemophilia* demonstrated the benefits of a prophylactic (preventive) treatment regimen for children with severe hemophilia B using a recombinant factor IX (rFIX) product. The lead author of the study was Paul Monahan, MD, Gene Therapy Center, University of North Carolina at Chapel Hill. Monahan is also a member of the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC).

The use of prophylaxis to treat children with hemophilia A is well documented. But there is limited data for such use in children with hemophilia B. The study included 25 children, six years old or younger, with severe hemophilia B. In all, 22 of 25 (88%) of the children received routine prophylactic therapy (one to two infusions per week) with BeneFIX[®], a rFIX product manufactured by Wyeth (a part of Pfizer), which also sponsored the study.

The therapy typically lasted more than six months. Investigators reported an average of less than one bleed per year and a near complete prevention of spontaneous breakthrough hemorrhages.

The majority (77%) of the children exhibited no spontaneous breakthrough bleeds, while approximately a third (32%) experienced no bleeding. Breakthrough bleeds that did occur were resolved with 1 or 2 infusions of rFIX in 89% of episodes. Though the patient group included children who had previously experienced multiple joint bleeds, 68% of the study subjects experienced no joint hemorrhaging. Investigators also reported that safety had been established by the low incidence of treatment-related adverse events. Further, the authors reported that the therapy was well tolerated by patients with central venous access devices.

The study, *Safety and Efficacy of Investigator-Prescribed BeneFIX Prophylaxis in Children Less Than 6 Years of Age with Severe Haemophilia B*, was published online January 4, 2010, in the journal *Haemophilia*.

What Is An Inhibitor???

In some patients with hemophilia, the immune system produces an antibody that inhibits the action of replacement blood products and prevents clot formation. This antibody is known as an inhibitor. The presence of an inhibitor makes the treatment of bleeding episodes more difficult. An inhibitor destroys the clotting factor before it has a chance to stop the bleeding. The reason inhibitors develop is uncertain; however, they occur more frequently in people with severe forms of hemophilia, particularly factor VIII deficiency, because of their need for more frequent infusions. Inhibitors tend to develop within the first one to three years of treatment, typically between the 50th and 100th exposure days.

Inhibitors are often discovered by laboratory testing during regular physician visits. An inhibitor is also suspected when bleeding does not stop after being treated with factor concentrate. Confirmation of an inhibitor is made using a blood test called the "Bethesda inhibitor assay." This test measures the presence and amount of antibodies directed against a coagulation factor in a person's blood after being exposed to factor.

Treating a person who has inhibitors can be a challenging experience for both the patient and the healthcare team. Often, the treatment is a two-fold process. First is to manage bleeding episodes and second is dealing with the inhibitor itself. Dealing with the presence of inhibitors can take months or even years of treatment.

It is important to note that proper diagnosis and treatment of inhibitors is complex, and there are many variables affecting treatment choice; no two patients or situations are identical. In all cases, these choices should be discussed with appropriate healthcare providers with expertise in this area, available at your local Hemophilia Treatment Centers.

Contact NYCHC if you would like to be put in touch with a family dealing with inhibitors; remember, you are not alone.

HTC Reminder: Remember to schedule your comprehensive visits!



For a complete list of Hemophilia Treatment Centers throughout the country visit
<http://www2.cdc.gov/ncbddd/htcweb/htc/htclist.asp>

Long Island Jewish Medical Center

Hemophilia Treatment Center
Phone: (718) 470-7380

Mount Sinai School of Medicine

Hemophilia Treatment Center
Phone: (212) 241-8303

Weill Medical College of Cornell University New York-Presbyterian Hospital

Hemophilia Treatment Center
Phone: (212) 746-3400



BLEEDING DISORDERS RESOURCE NETWORK, LLC
Bringing Quality Service to Our Community



BDRN is committed to supporting the bleeding disorders community. By working together with consumers, treatment professionals, and insurers we can help give you peace of mind and better control over your bleeding disorder. It is our goal to keep both ourselves and our clients educated about their disorder in this rapidly changing environment so that they can maintain their best possible lifestyle. It is also our goal to employ competent, caring, and well-trained individuals who are responsive to the needs of our clients, their families, and the community we serve.

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BLEEDING DISORDERS RESOURCE NETWORK, LLC
Bringing Quality Service to Our Community

BDRN has identified five core values that we use as a guide in carrying out our day-to-day activities:

- 1. Respect:** We recognize the worth of the individual and care for each one as a whole person.
- 2. Integrity:** We strive to provide the best service with the highest standards as the essence in everything we do.
- 3. Service:** We provide compassionate and attentive care in a manner that inspires confidence.
- 4. Excellence:** We provide superior clinical outcomes in an environment that is safe for both our clients and caregivers.
- 5. Stewardship:** We take personal responsibility for the efficient and effective accomplishment of our mission.

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BAXTER'S COMMUNITY PROGRAMS

ADVANCE YOUR EDUCATION. ADVANCE YOUR LIFE.

Inspired by the community, **Education Advantage** is the new scholarship program—supported by Baxter—for adults and teens with hemophilia A, including those with inhibitors.

The **Education Advantage** program is entirely managed by Scholarship America, the nation's leading nonprofit scholarship administrator. Baxter has no influence on the selection of scholarship recipients.



Call **1.877.544.3018** or visit
www.myeducationadvantage.com.
Apply now! Applications due 4/16.

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NYCHC
 NEW YORK CITY HEMOPHILIA CHAPTER

Some of the ways NYCHC is making a difference...

- ¥ Supporting our local Hemophilia Treatment Centers
- ¥ Contributing to camps for children with bleeding disorders
- ¥ Sponsoring a child from Nepal with hemophilia through Save One Life
- ¥ Advocating for the bleeding disorder community at Washington and Albany Days
- ¥ Funding research through the National Hemophilia Foundation's JGP Research program



Fundraising Tips: How to Raise \$500 in 7 Days!

Day 1: Sponsor yourself	\$50.00
Day 2: Ask 4 family members for \$25 each	\$100.00
Day 3: Ask 5 co-workers to contribute \$15 each	\$75.00
Day 4: Ask 5 friends to donate \$15 each	\$75.00
Day 5: Ask 5 neighbors to sponsor you for \$15 each	\$75.00
Day 6: Ask your boss for a company contribution of \$50	\$50.00
Day 7: Ask 3 businesses you frequent for a donation of \$25 each	\$75.00
TOTAL AMOUNT RAISED: \$500!	

Uncomfortable about asking for a donation?

Remember:

- how many times has someone asked YOU to sponsor THEM? It's your turn!
- you are NOT asking for yourself- you are raising money to help others.
- everyone has the option to say "no" - it never hurts to ask!
- explain to them why this is important to you- many people will want to help.

Use Email and Facebook in addition to in-person asks. Be sure to visit our website www.hemophilia.org/walk (select New York from drop down menu).

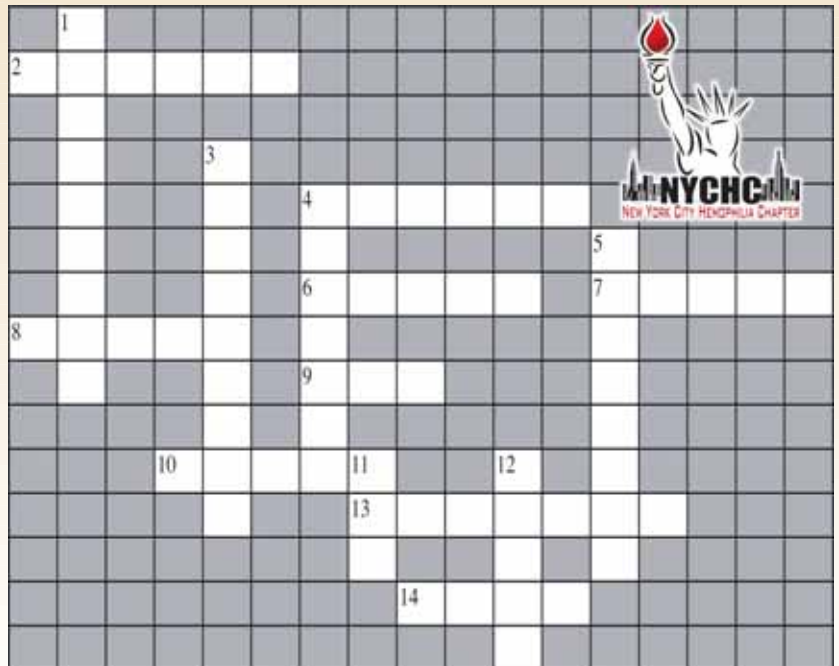
Life with a bleeding disorder can be stressful. Take a break. Do a puzzle!

ACROSS

- A special container used to throw away needles.
- Sterile water that you mix with factor.
- Hemophilia was once known as "The _____ Disease".
- Your local hemophilia chapter organization.
- A small square pad of cotton cloth.
- The largest national hemophilia organization in America.
- Factor is used to treat a _____.
- Type of disinfectant.
- Sunday, June 6, 2010 is the NYC Hemophilia _____.

DOWN

- Factor 9 hemophilia is also sometimes referred to as _____ disease.
- A type of infusion needle.
- A tube used to hold the mixed factor.
- The process of getting factor into your body.
- April 17 is World Hemophilia _____.
- World Hemophilia Day is celebrated in more than 100 countries around the _____.



Answers: Across: 2. Sharps 4. Saline 6. Royal 7. NYCHC 8. Gauze 9. NHF 10. Bleed 13. Alcohol 14. Walk
Down: 1. Christmas 3. Butterfly 4. Syringe 5. Infusion 11. Day 12. World

NYCHC Summer Camp Connection It's that time of year! Summer Camp!

Jacqueline Lefkowitz, LCSW, MA, MSW

New York Comprehensive Center for Hemophilia and Coagulation Disorders New York Presbyterian Hospital-Weill Cornell Medical Center

Summer camp can be a very positive experience for children and teens with bleeding disorders. Going to camp can enable them to experience an increased sense of independence and mastery over their bleeding disorder. It can contribute to their overall emotional and social development. Camp can provide children with the opportunity to forge deep and long lasting social connections with other children with the same or similar medical condition. It is also just a fun way to spend a week away from home during the summer. Camp is often the only opportunity for children and teens from the city to actually be in the country.



Camps such as Double "H" Ranch in Lake Luzerne, NY serve children with various chronic illnesses and are free of charge and fully staffed by trained medical professionals. Many of these individuals work with children with bleeding disorders and other chronically ill children in medical settings all year round. Counselors at these camps are highly trained to be sensitive to the needs of children with medical issues. Many of these counselors have bleeding disorders or other chronic illnesses themselves and have felt they have so greatly benefitted from their own camp experiences that they chose to work as counselors at camp as soon as they were old enough.

Parents often feel more willing to provide consent for their children to participate in activities ordinarily beyond their comfort zone when they send their children to a camp staffed by trained medical professionals and specially trained counselors. For a child with a bleeding disorder, participating in a previously "off-limits" activity such as river rafting and high ropes climbing can be a great thrill and major accomplishment. Of course, you should ask your hematologist about any activity you are unsure is safe for your child.

If you have never sent your child to camp before, consider whether he or she is emotionally and medically ready to go for the first time. I would advise any parent in the consideration stage to address any questions or concerns about readiness with the hemophilia center social worker and medical team.

Once you have made the decision, completed your application, and your child has been accepted for the session of your choice, before you leave home, make sure to pack your child's factor and other medications such as Amicar along with his or her other belongings so that they are readily accessible and available for treatment use.

If your family has financial difficulty transporting your child to camp, please consult with your HTC social worker or chapter advocate. They can determine if you and your child qualify for financial assistance to help you fund your travel expenses.

Lastly, if you are interested in sending your child to a camp serving only children with hemophilia and bleeding disorders, the two closest are in upstate NY: Camp High Hopes (for boys) and Camp Little Oak (for girls).

2010 Camp Calendar

CAMP HIGH HOPES

Exclusively for boys with bleeding disorders
Aldersgate Camp, Brantingham, NY
Ages 7-17/ August 15th-21st
For Application and Info
Contact: bobgraham04@msn.com
Visit website for more info: www.camphighhopes.org

CAMP LITTLE OAK

Exclusively for girls with bleeding disorders
(female siblings and carriers welcome if space permits)
Aldersgate Camp, Brantingham, NY
Ages 7-17/ August 8th-13th
For Application and Info
Contact: homer.everson@gmail.com
Female volunteer counselors needed for girls camp;
NYCHC can help pay for volunteer travel expenses.
Contact: jeri.krassner@nyhemophilia.org

DOUBLE "H" RANCH

For children with various chronic diseases
Lake Luzerne, NY
Ages 6-16 co-ed
Various weeklong sessions to choose from
Application deadline April 15th
Visit website for more info: www.doublehranch.org



**MARK YOUR
2010 CALENDARS!**
Check out our website
www.nyhemophilia.org
for full details

ALBANY ADVOCACY DAYS

Sunday & Monday, March 21st and 22nd

WORLD HEMOPHILIA DAY

Saturday, April 17th

NYC HEMOPHILIA WALK

Kick Off Event
Thursday, May 6th

Hemophilia Walk
Sunday, June 6th

