



The Bleeding Times

Serving the Bleeding Disorder Community

Spring/Summer Edition 2009

www.nyhemophilia.org

New York City Hemophilia Chapter

New York City Hemophilia Chapter

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First Annual Meeting & Holiday Party A Great Success!

NYCHC had its first annual meeting/holiday party on Dec. 14, 2008. Over 125 people enjoyed a buffet lunch and speakers Dr. Donna DiMichele and Val Bias. And kids were treated to a visit from Santa!

Special thanks to our exhibitors & sponsors:

- ACCREDO/HEMOPHILIA HEALTH SERVICES
- AFFINITY BIOTECH
- AHF, INC.
- BAXTER BIOSCIENCE
- BAYER HEALTHCARE*
- BLEEDING DISORDER RESOURCE NETWORK, LLC
- CSL BEHRING*
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- NEW YORK BLOOD CENTER, HEMOPHILIA SERVICES
- TRINITY HOMECARE*, A WALGREENS COMPANY
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*lunch sponsors

We Need Your Support! Become an NYCHC member today!

- Family membership (one year): \$25 Individual membership (one year): \$15

Your additional contribution will support the chapter's efforts to provide important education and support services for New Yorkers with bleeding disorders. Enclosed is an additional tax-deductible contribution of \$25 \$50 \$100 \$250 \$500 Other _____

Make check payable to: New York City Hemophilia Chapter
Mail to: NYCHC, 358 Fifth Avenue, Suite 401, New York, NY 10001

Name(s): _____

Ages of child (ren): _____

Address: _____

Phone: _____

Email address: _____

Family member with bleeding disorder? Yes No Type: _____
Inhibitors? Yes No

Age of family member _____ Name _____

If you use a Hemophilia Treatment Center, which one? _____

If not, where do you go for treatment? _____

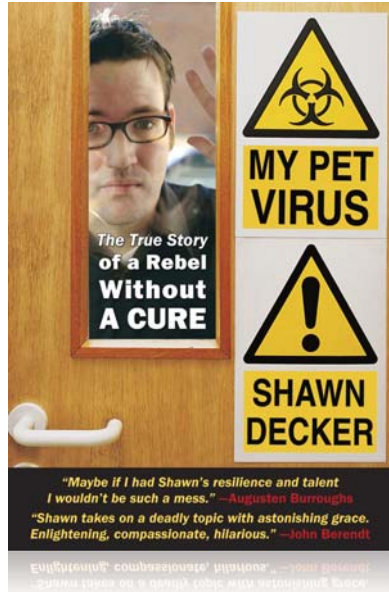
Other affiliation with community (please specify) _____

In this issue...

- NYCHC sponsors a child through Save One Life
- NYC Hemophilia Walk 2009
- Research News
- Documentary Film "Bad Blood"

Autobiography
My Pet Virus
 by Shawn Decker

While hemophilia and AIDS are not typically chuckle-worthy, Shawn Decker finds surprising humor in his own bouts with the illnesses (his parents, he notes, inexplicably named him Shawn Timothy Decker, or "S.T.D."). He never wallows in self-pity, even after contracting HIV from tainted factor product. Instead, Shawn becomes something of an AIDS advocate, leading to a photo op with Al Gore and a reunion with his boyhood hero, wrestler Ric Flair. Shawn, along with his HIV negative "wife partner" Gwenn, currently tours the country educating young people about safe sex while continuing to blog about the adventures with his pet virus. **My Pet Virus** is a sweet reminder that no matter how bad things get, there's no reason to stop laughing.



For more info visit <http://www.shawnandgwenn.com/books/>
 Sold on Amazon.com

**NYCHC sponsors
 a child through
 Save One Life**

With money donated from attendees at our annual meeting, NYCHC is able to sponsor a nine year old boy from Nepal who has factor VIII deficiency, through Save One Life organization. We are making a difference!

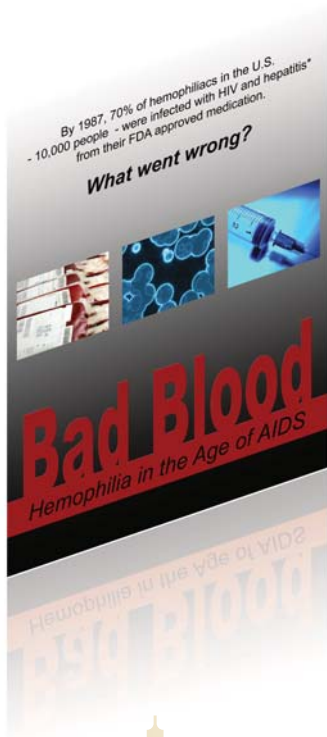
www.saveonelife.net



Of interest:
Documentary Film
Bad Blood

By 1987, 70% of hemophiliacs in the United States - 10,000 people - were infected with HIV and hepatitis from their FDA approved medication. They leave behind a legacy of suffering that reminds each of us what can happen when the "system" fails. BAD BLOOD is a cautionary tale, bringing together patients, doctors, drug manufacturers, and government regulators to recollect how the worst medical disaster of the 20th Century was allowed to occur and cautions us to remember, remain vigilant, and demand a safer system.

BAD BLOOD is a work-in-progress and additional funding is needed to complete this important film. To learn more please visit: www.necessaryfilms.com



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 New York City Hemophilia Chapter (NYCHC) Group
<http://www.facebook.com/group.php?gid=33260004623>

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- Arranging home infusion nursing services

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Mandy McCullough
800-652-5242

800-243-4621
AHF@AHFinfo.com
www.AHFinfo.com



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be part of the link crowd

Come join us for an interactive experience to...

- **Learn** and provide feedback about exciting new programs and resources
- Share **insights** about hemophilia
- Increase your **knowledge** about the latest in hemophilia treatment and support

Contact Amy Kerico today at 732-995-8610 to discover when the next LINK gathering will be happening in your area.



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link
learning, insights, and knowledge



Advertise in our next newsletter!
for more info email: shari.bender@hemophilia.org

Mark Your Calendars for These Events

Check our website www.nyhemophilia.org for full details or RSVP melissa.penn@nyhemophilia.org



**Spring Event at the
Sports Museum of America
Sunday, March 8th - noon**



**NYC Hemophilia Walk 2009
Riverside Park, NYC**

- Start forming your teams now
- Begin a letter writing/ email campaign

NYCHC Camp-connection Is Your Child Enrolled In Summer Camp?

Parents and children alike rave about Summer Camp. Campers have wonderful experiences away from mom & dad in a safe and caring (and FUN!) environment. Swimming, Biking, Campfires, Basketball, Archery, Crafts and lots of great stuff! Of course, camp provides on-site medical care and supervision.

Camp tuition is free, but transportation and travel arrangements to and from camp are the responsibility of the camper's family. Contact NYCHC if financial assistance for transportation is needed.



CAMP HIGH HOPES

Exclusively for boys with bleeding disorders
Aldersgate Camp, Brantingham, NY
Ages: 7-17/ August 16-22
For more info on attending or volunteering-
contact Bob at 315-463-5354 or email
Bobgraham04@msn.com

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 24-29
For more info on attending or volunteering-
contact Homer at 315-876-4123 or email
homer.everson@gmail.com

DOUBLE "H" RANCH

For children with various chronic diseases
Lake Luzerne, NY
Ages 6-16 co-ed
Application deadline: April 15, 2009
Call 518-696-5676 for applications or info
www.doublehranch.org

THE HOLE IN THE WALL GANG CAMP

For children with various chronic diseases
Ashford, CT
Ages 7-15 co-ed
Application deadline: April 1, 2009
Call 860-429-3444 for applications or info
www.holeinthewallgang.org

What Parents Are Saying About Camp:

"Rose has been going to Camp Little Oak for 3 years- having a camp specifically for girls with bleeding disorders provides a one-of-a-kind bonding experience. Rose has gained such independence and confidence from her time away at camp and she can't wait to go back again this year!"
- Mom of 11 year old with hemophilia

"I really can't say enough good things about the Hole in the Wall Gang camp. From the moment you arrive on the grounds, you know that it's a special place. The counselors and volunteers truly care about the children and try their best to make it an unforgettable experience. After three years of hearing Tai-yan talk year-round about how wonderful camp is, I can definitely say they're achieving that objective!"- Mom of 10 year old with hemophilia

KIDS CORNER:

WORD SCRAMBLE

- 1) **yesrgin** _____
- 2) **trofac** _____
- 3) **eleden** _____
- 4) **moehiilhpa** _____
- 5) **oldbo** _____

Answers: Syringe, Needle, Hemophilia, Blood

EVENT CALENDAR

Check our website www.nyhemophilia.org for full details or RSVP melissa.penn@nyhemophilia.org



**Spring Event at the Sports Museum of America
Sunday, March 8th - noon**



**NYC Hemophilia Walk 2009
Riverside Park, NYC**
• Start forming your teams now
• Begin a letter writing/ email campaign

HTC Reminder: Remember to schedule your comprehensive visits!



For a complete list of Hemophilia Treatment centers throughout the country visit http://www.cdc.gov/ncbddd/hbd/htc_list.htm

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

RESEARCH NEWS

Promising Animal Studies Continue the Quest for a Cure and Longer Lasting Factor

A team of Wisconsin researchers recently increased factor VIII (FVIII) levels in mice with hemophilia A and inhibitors through a specific type of gene therapy involving bone marrow. The technique also involves platelets, which are produced inside the bone marrow. The lead investigator of the study was Qizhen Shi, MD, PhD, Department of Pediatrics, Medical College of Wisconsin in Milwaukee. Dr. Shi's research is currently being funded through the National Hemophilia Foundation's Career Development Award Program.

Shi and colleagues effectively removed portions of bone marrow from mice, genetically modified the stem cells in them and then returned the altered marrow to the mice. This approach triggered "normal" production levels of FVIII. The FVIII was then delivered into the bloodstream by the platelets. In lab tests, the majority of the hemophilia A mice with inhibitors showed healthy levels of FVIII and significantly less bleeding following delivery of the therapy. Although the reported results are promising, additional animal studies, followed by eventual human trials will need to be completed before this kind of therapy becomes an option for patients.

The study, "Syngeneic Transplantation of Hematopoietic Stem Cells That are Genetically Modified to Express Factor VIII in Platelets Restores Hemostasis to Hemophilia A Mice with Pre-existing FVIII Immunity," was published in the October 2008 issue of Blood.

Source: Medical News Today, November 14, 2008