



The Bleeding Times

Serving the Bleeding Disorders Community

Fall / Winter Edition 2010

www.nyhemophilia.org

New York City Hemophilia Chapter

New York City Hemophilia Chapter

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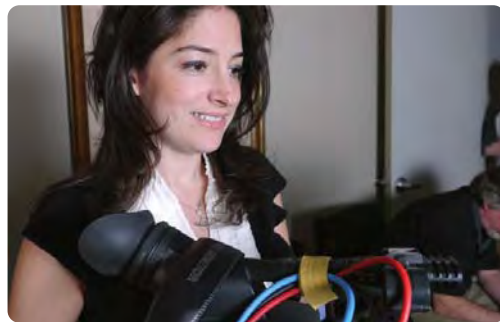
Bad Blood has New York and Washington Premieres

Special NYCHC Screening Scheduled for November 22

BAD BLOOD: A Cautionary Tale had its New York City premiere on July 28, 2010, followed by a Washington, DC premiere on September 29th - and now NYCHC has scheduled an additional New York City screening for November 22 at the Anthology Film Archives in the East Village. The full-length documentary by filmmaker Marilyn Ness "chronicles how a 'miracle' treatment for hemophilia became an agent of death" when in the 1980s, tens of thousands of people with hemophilia became infected with HIV and hepatitis C because of drugs made from tainted plasma.

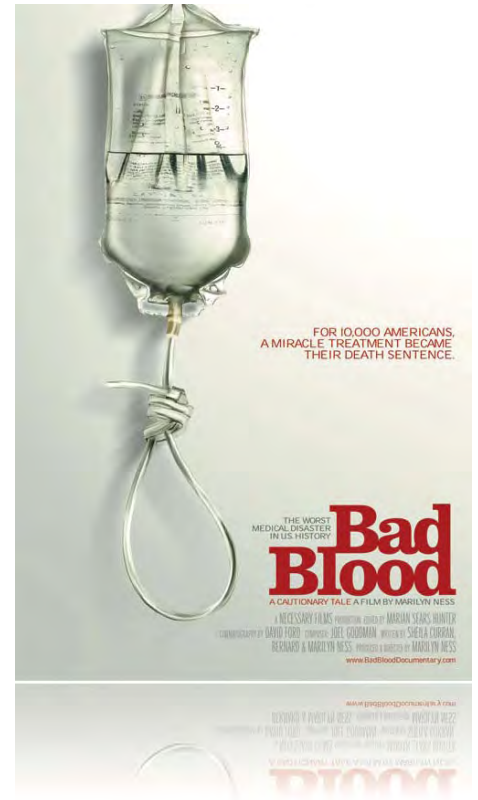
"We were thrilled that this tremendously important film had its premiere in New York before a diverse audience, but not everyone had a chance to see it that night" said Melissa Penn, NYCHC's Executive Director. This is an opportunity for our member families, their friends and other interested New Yorkers to see this astounding and heart-wrenching story."

The premieres were presented with the participation of a group of outreach partners, including the Committee of Ten Thousand (COTT), the Hemophilia Federation of America (HFA), the National Hemophilia Foundation (NHF) and others. NYCHC and other bleeding disorders chapters and associations are working with many of the same partners to arrange screenings across the country. Like the premieres, the November 22 screening in New York City will feature a Q&A session with Ms. Ness, NHF CEO Val Bias, and others.



Bad Blood Filmmaker Marilyn Ness

Calling her work "a cautionary tale," Ms. Ness views the tragedy she documents as a systemic failure of epic proportions. She hopes the film will inspire community members, government leaders, pharmaceutical companies and others to take the steps necessary to ensure that nothing like it ever happens again. "I made a conscious choice to use the historical record including news footage, actual memos, and personal photographs - not recreations - so the facts speak for themselves and reminds audiences that tragedy of this magnitude can unknowingly unfold right before our eyes," Ness said. "Emerging from tragedy, I hope, is a story of caution and inspiration, as victims of medical disaster fight to change the systems that failed them."



A limited number of tickets to the November 22 screening of *Bad Blood* will be available to NYCHC members at no cost. Please watch the NYCHC Website at www.nyhemophilia.org and the NYCHC Facebook page at www.facebook.com/NYCHemophiliaChapter for more information.

Hope Woodcock Receives NYCHC's 2010 Award of Distinction

Hope Woodcock, a registered nurse with a distinguished record of devoted service to the bleeding disorders community in New York and beyond, has been named the 2010 recipient of the New York Hemophilia Chapter's Award of Distinction. The award, presented at NYCHC's Fall Fundraiser in October, is given to an individual who has shown an unwavering commitment to the bleeding disorder community through service and volunteerism.



**2010 Award of Distinction
Recipient Hope Woodcock**

Hope has worked as a nurse since the 1980s. Her involvement with bleeding disorders goes back to 2000. She has held the Blood Disorder Center Coordinator position at United Health Services Hospitals in Johnson City, NY since 2004. She has also spent nine seasons as the nurse at Camp High Hopes, a non-profit camp for boys 7 to 17 with hemophilia or VWD, and has recently taken on the role of Health Director for the camp. In 2005, Hope co-founded Camp Little Oak, a non-profit camp for girls 7 to 17 with hemophilia or VWD, carriers and siblings.

Hope has served on the National Hemophilia Foundation's Nurse Working Group, is currently the nurse representative on NHF's Ethics Committee and is the co-chair of the nursing working group for Region II. She recently authored the Needle Know-How, Calming Kids' Anxiety Over Needles and Infusions for NHF's HemAware magazine.

As a volunteer, Hope has worked with the Bleeding Disorder Association of the Southern Tier and the Southern Tier AIDS Program, for whom she chairs an annual walk team. She has also participated in NYCHC's walk, and has helped teach infusion at our annual holiday event.

"NYCHC is delighted to have this opportunity to honor Hope, who has done so much for New Yorkers affected by bleeding disorders" said chapter president Shari Bender. "Hope is a shining example of what service and volunteerism are all about," Bender said.



NYC Hemophilia Walk Sets New Records!

The 2010 New York City Hemophilia Walk, held on June 6th in Riverside Park, set new records this year. The event attracted thousands of walkers and sponsors who raised more than \$200,000 to support local and national programs for people with bleeding disorders. Now in its fifth year, the NYCHC event was the inspiration for what is now a national event hosted by chapters of the National Hemophilia Foundation in fourteen cities across the country.



The Walk is designed to engage individuals and families from throughout the community and beyond in a day of fun for all age groups. At the same time, it raises crucial funds for local and national programs that focus on education, advocacy and research.

NYCHC is grateful to all of the walk sponsors, team captains, walkers, volunteers and staff who worked so hard to make the event a great success. The 2011 Walk will take place on Sunday, June 5. Mark your calendars and stay tuned for information!

HTC Reminder: Remember to schedule your comprehensive visits!



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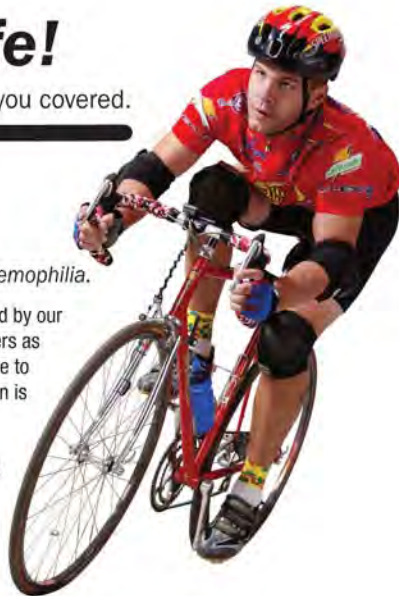
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Some of the ways NYCHC is making a difference...

- 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



Legislative Update

FEDERAL: Ban on Lifetime Caps Goes Into Effect

On September 23rd, the first provisions of the nation's new healthcare law went into effect. For people with hemophilia and other high-cost chronic diseases, the most significant change is probably the elimination of lifetime caps for new and renewed health insurance policies. In the past, many policies had lifetime limits as low as one or two million dollars. Some individuals went through these limits in as little as a year or less. Under the new law, these lifetime limits will be eliminated for plans issued or renewed on or after Sept. 23. Those who have maxed out because of the caps but remain eligible for coverage must be reinstated on the first day of their new plan year that begins on or after Sept. 23. The bleeding disorders community played a significant role in making sure the issue of lifetime caps was visible and ultimately included in healthcare reform.

STATE: Prescription Drug Pricing Bill Goes to Governor

A bill prohibiting Tier IV drug pricing in New York State has passed in the legislature and as of this writing is awaiting Governor David Paterson's signature. As the cost of prescription drugs continues to rise, health insurance plans have responded by creating new cost-sharing "specialty tiers" within their prescription drug formularies. In several states, consumers with chronic diseases and life-threatening illnesses are charged a copayment based on a percentage of the drug's cost - typically 25%-33% of the cost of the drug per month - instead of a flat co-payment. This practice, known as Tier IV pricing, is often applied to biologic drugs which are usually injectable and very expensive. Although the practice has for the most part not been applied to clotting factor used to treat bleeding disorders, it may only be a matter of time before insurance companies treat factor as a Tier IV drug in order to cut their costs. The New York bleeding disorders community was instrumental in getting this legislation introduced and passed through efforts that included visits to legislators during "Albany Days," as well as phone call and letter campaigns. For information on how to get more involved in these types of advocacy efforts, please contact the New York City Hemophilia Chapter.



Join Us for the Holidays!

The NYCHC Annual Meeting and Holiday Party will be held on Sunday, December 12, 2010 from 11:30am - 4:00pm in New York City. Families and individuals with bleeding disorders are invited to join us for food, exhibits, education and holiday fun. Programs geared for children and adults will be available, including informative sessions on the latest developments in treatment, sports and physical activity and much more. All children attending will receive a special gift! There is no charge to attend this event but prior registration is required. To register or for more information, please watch our Website at www.nyhemophilia.org and our Facebook page at www.facebook.com/NYCHemophiliaChapter.



Rose Bender demonstrates self-infusion at an educational session during NYCHC's 2009 Annual Meeting and Holiday Party



NYCHC President Shari Bender (l) and Fashion Designer Dana-Maxx Pomerantz select fabric for the "Victory for Women" dress, raising awareness and funds for women's blood disorders.

Victory for Women

The New York City Hemophilia Chapter is working with fashion designer Dana-Maxx Pomerantz on a unique pilot program to help raise awareness and funds for women's blood disorders. Ms. Pomerantz is creating an exclusive "Victory for Women" dress that will be available starting in November through www.dana-maxx.com. Attendees at NYCHC's Fall Fundraiser will get a "sneak preview" of the dress which will be worn at the event by chapter president Shari Bender, with the designer in attendance. The dress will also be previewed at NHF's Annual Meeting on November 11-13 in New Orleans.

A portion of the proceeds from the sale of the dress will be donated to the National Hemophilia Foundation's "Victory for Women with Blood Disorders" initiative. The program incorporates education, advocacy, and support for women diagnosed with a blood disorder and raises awareness among women who have not yet been diagnosed.

NYCHC's dress campaign with Dana-Maxx is one of several local and national efforts designed to support this important initiative. NHF is working with noted photographer Patrick McMullan on a calendar featuring women affected by blood disorders. The calendar will have its debut at NHF annual meeting.

For more information on the Victory for Women dress campaign, visit www.nyhemophilia.org. To order the Victory for Women dress, visit www.dana-maxx.com. For more information on the NHF's Victory for Women with Blood Disorders initiative, visit www.hemophilia.org.

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RESEARCH UPDATE

Swedish Study Assesses Osteoporosis Prevention in People with Severe Hemophilia

In May researchers in Sweden published the results of a study analyzing whether physical activity, accompanied by a long-term prophylactic (preventive) treatment regimen, is a significant determining factor in the prevention of osteoporosis in patients with severe hemophilia. The lead investigator of the study was Mohamed Mansour Khawaji, Malmö University Hospital, Lund University.

Osteoporosis is characterized by loss of bone mass and degeneration of bone tissue. Left untreated, bones become fragile and are prone to fractures, especially in the hip, spine, neck and wrist. A bone mineral density (BMD) test helps determine whether a patient has osteoporosis. Physical activity, particularly weight-bearing exercise, is one of the key contributors to maintaining and enhancing bone strength.

Of the 30 patients (28 with hemophilia A, 2 with hemophilia B), all received regular long-term prophylaxis (2-3 factor infusions per week) for an average of 29.5 years. The majority (25) started the regimen in early childhood (average age was 2 years), five began prophylaxis in late childhood and adolescence (ranging from 7-15 years old). An enhanced BMD test was conducted in each patient.

Physical activity was assessed through a "Modifiable Activity Questionnaire," a self-reporting tool used on leisure and occupational activities for the previous 12 months. Nearly all participants reported engaging in weight-bearing activities (96.6%). Seventeen (56.6%) participated in "vigorous activities" such as wood chopping and jogging, while 18 (60%) engaged in nonweight-bearing activities, including cycling and swimming. Walking was also a commonly cited activity (63.3%).

"In conclusion, with adequate long-term prophylaxis, patients with hemophilia are maintaining bone mass, whereas the level of physical activity in terms of intensity and duration play a minor role. In addition, these results may support the proposition that the responsiveness to either an increase or a decrease in mechanical strain is probably more important for bone mass in children and adolescents rather than in adults and also supports the importance of starting prophylaxis early in life so that the children can lead active life and normal bone density when they grow up," reported the authors.

The study, "Physical Activity for Prevention of Osteoporosis in Patients with Severe haemophilia on Long-term Prophylaxis," was published in the May 2010 issue of Haemophilia.