

HEMOPHILIA OUTLOOK

A Newsletter of

The Hemophilia Association of New York, Inc.

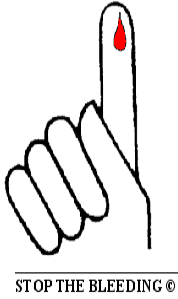
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FALL 2015



The Feldenkrais Method

HANY is offering 12 free *Feldenkrais classes* to our clients and significant others. Starting September 1st through November 17th, 2015 (on Tuesdays).

The Feldenkrais Method is a remarkable approach to human movement, learning and change originally developed by Moshe Feldenkrais. The method is based on sound principles of physics, neurology and physiology, and the conditions under which the nervous system learns best.

Feldenkrais (sometimes called Feldenkrais therapy) is recognized for the strategies it employs to improve posture, flexibility, coordination, athletic and artistic ability and to help those with restricted movement, chronic pain and tension (including back pain and other common ailments), as well as neurological, developmental and psychological problems.

For more information on the *The Feldenkrais Method* call 212-727-1210 or visit, www.feldenkraisfoundation.org.

To register for the *Feldenkrais classes* please contact Annie to at 212-682-5510 or annhany@bestweb.net. *Classes can be attended out of sequence.*

HANY Scholarship Awarded

Sixteen candidates are sharing \$46,500 in HANY scholarship awards this academic year.

Among the stipends given are the "Isabel K. Brach Award" (this year to a Psychology major), the "Dr. Margaret Hilgartner Award" (this year to a Physician Assistance major), the "Dr. Margaret Karpatkin Award" (this year to a Nursing major), the "Adam Lynch Award" (this year to a Dance Movement Therapy major) and the "Matthew Lee Greer Children's Foundation Award" (this year to a Liberal Arts & two Psychology majors).

Eligibility now extends from persons with certain diagnosed bleeding disorders to carriers and unaffected children of parents with qualified bleeding disorders. *April 1, 2016 is the deadline for applying.* Call HANY for an application.

Other Scholarships Available...

For a full list for the various scholarship programs look at the website of LA Kelley Communication (www.kelleycom.com).

Si usted necesita traducción or interpretación en español de algún artículo en este letras de noticias por favor de llamar a Ann Pérez o Gabriela Blum al (212)682-5510.

Fall Festival Pumpkin Picking

The Hemophilia Association of New York invites children with bleeding disorders (17yrs & under), siblings and parents to come to the Fall Festival Pumpkin Picking. *You must be a registered client with HANY.*

Where: Dees Nursery (Pumpkin Patch)
69 Atlantic Ave
Oceanside, NY 11572
516-678-3535
www.deesnursery.com

When: October 10, 2015 (Saturday) @
2:00pm - 5:00pm

RSVP is Required to attend this event by **October 2, 2015**. Please contact Annie at (212) 682-5510 or email at @
annhany@bestweb.net

**Vouchers for activities will be provided.*

Prepare Ahead For School

Preparation for the school year is best done before the first day of school. Contact the principal, school nurse and your child's teachers (including gym instructors) to explain his or her special needs. Give them the name of his doctor and hospital and a telephone number at which you can be reached at any time.

Your child should be able to participate in all of his classes, including physical education. However, if he experiences frequent bleeds during gym class, your doctor or the physical therapist at the HTC can work with the school to arrange a modified exercise program.

HANY can provide you with free pamphlets for educators and school nurses, to explain hemophilia. Call us for copies. Your

treatment center is also available as a resource for starting the school year right.

Fall 2015 Bleeding Disorders Advocacy Network Fall Family Retreat

The dates for the BDAN Fall Family Retreat are **October 10 - 12, 2015 Columbus Day weekend**. The 2015 Theme is "Lives In Motion". 2015 is the 11th year of the Fall Family Retreat, and they are excited to share it with you! This 3 *day/2 night retreat* is free for adults and families with bleeding disorders from New York and nearby states. Reservations are booked on a first apply, first accepted basis. If you have questions about the retreat you're always welcome to visit the website at www.bdaninc.org Or contact Bob Graham at email: bobgraham04@msn.com or 315-396-2944.

Bleeding Disorders Association of Northeastern NY (BDANENY) Carrier's Retreat October 16-18, 2015

Learning that you are carrier of hemophilia can be an emotional and challenging time. Your reaction to being a carrier often depends on the experiences you have had with members of the family who have been dealing with hemophilia. You are not alone. Join other women with a carrier status (ages 18-up) to discuss how a woman becomes a carrier, what to do when you find out you are a carrier and how this will affect your future.

There will also be opportunities for hikes, quiet reading on the verandas, joining others around a bon fire and delicious meals.

This retreat is limited to women who are carriers of hemophilia ages 18 and up. Space is limited. You must pre-register! Register by calling Laura at 518-729-3577 or email memberservices@bdaneny.org.

SAT Prep Course

HANY is offering free SAT prep course to our clients. With more than one million students taking the SAT test each year and ever-increasing competition to get into the best universities, the stakes are high for preparing for college. SAT test prep can help your teen navigate this big test with ease, earning impressive scores along the way. If you're interested in participating please contact Annie at 212-682-5510. There are only ten spots available!

Obamacare numbers revealed

(Crain's Health Pulse, July, 30, 2015)

The New York State of Health signed up 2.1 million people during the 2015 open enrollment period, more than double the number of New Yorkers who registered with Obamacare in 2014, the program's inaugural year. The huge influx of newly insured people boosted the market shares of some of the state's insurers. A report released July 29 by the state Department of Health indicates that 1.6 million people enrolled in Medicaid plans. Another 415,000 bought commercial plans through NYSOH. The four largest plans in the state—Fidelis Care, Health Republic, Healthfirst and Empire BCBS—represented a collective 59% of the market share of the plans sold on the state exchange, compared with 65% in 2014. The small-business exchange enrolled 3,708 such firms as of April. On average, employers who purchased through the SHOP exchange contributed 70% of the cost of employees' coverage. The report noted that 62% covered dependents, up 14% over 2014. Collectively, 14,628 employees and dependents are covered through the SHOP, up nearly 50% over the first enrollment period.

Nearly three-quarters of SHOP enrollees are insured by Health Republic (35%), Excellus BCBS (27%) and MVP (11%).

Preparing for School Trips and Activities

When it comes to school field trips and extracurricular activities, your child has the right to participate. A child cannot be denied participation because he or she needs medication or treatment, or requires special assistance. If a field trip is planned, the teacher should give you, your child, and the school administration enough time to put together a plan to meet your child's needs. In some cases, you or a school staff member who has been educated about your child's bleeding disorder may want to go along with the class. Work with the school to ensure that your child has access to medication at all school-related activities.

For a sample letter for Trips and Activities from the National Hemophilia Foundation see page 4.

Special Thanks

We would like to thank the following sponsors for their support of our Fundraising Events which enable HANY to achieve our mission of serving people with Bleeding Disorders.

*Bayer
Baxalta
Biogen
Bleeding Disorder Resource Network
CSL Behring
Grifols
Octapharma
Pfizer
Novo Nordisk*

SAMPLE LETTER – RECOMMENDED FOR:

After School Activity/School Trip

This is a sample letter. Please work with your Hemophilia Treatment Center (HTC) and, where applicable, your local school district to create a letter that works best for your child.

____ Name of Parent ____
____ Street ____
City, State, Zip Code
(**) ** - ** (cell)
(**) ** - ** (home)

[Date]

To: _____

Just a reminder for you that _____, ____ years old, has _____.
As you already know, _____ participates in all school activities. In an overnight situation like this, however, you need to keep several things in mind:

1. _____ should not engage in wrestling or contact sports like tackle football—all other sports are fine.
2. Although _____ has received a dose of factor, he may need additional treatment if other trauma does occur.
3. _____ is traveling with one dose of his factor in case of an emergency that would warrant his transportation to a hospital.
4. _____ can communicate to you if he is having an internal bleed, and please take him seriously.
5. Treat any cuts, scrapes, or bruises that he may get the same as you would with anyone else.
6. In case of nosebleed use pressure on the nose, a cool compress on the back of the neck, and keep his head forward.
7. _____'s medicine should be kept away from heat and freezing. It can remain out in his room with his stuff at room temperature.
8. Under no circumstances should _____ be given aspirin, ibuprofen (eg, Advil®), naproxen (eg, Aleve®), or any products containing those items, because they promote bleeding. He may only, and only if needed, take acetaminophen (eg, Tylenol®) products for pain or fever.

In case of emergency, _____'s health insurance is: _____; Group number: *****; Member number: *****; Electronic payer ID: *****; Phone number: (877)-***-****.

If you need to contact me, please call: _____ at (**) ** - ** (cell), or (**) ** - ** (home).

Have fun!