



Hemophilia OUTLOOK

A Newsletter of

The Hemophilia Association of New York, Inc.

131 West 33rd Street, Suite 11D, New York, NY 10001

Tel 212-682-5510 Fax 212-983-1114

Email: admin@hemophiliany.com

www.hemophilia-newyork.org

www.facebook.com/Hemophilia.Association.of.NewYork

 **FALL 2016** 

Family Educational Conference

Our first Family Educational Conference at Mohonk Mountain House. Programs, meals and rooms are covered by us.

All of the rooms have been spoken for. However, we have a waiting list in the event of any cancellations.

If you want to be on the waiting list, please contact us at (212) 682-5510 or email us at admin@hemophiliany.com

Where: Mohonk Mountain House

1000 Mountain Rest Rd,
New Paltz, NY 12561
www.mohonk.com

When: November 11 - 13

Supporters and Exhibitors of the Mohonk Family Weekend

We would like to thank the Supporters and Exhibitors of the Mohonk Family Weekend:

Hemophilia Services Consortium, Pfizer, CSL Behring, Shire, Bayer, Grifols, Biogen, Novo Nordisk, Octapharma, Aptevo, and Hemophilia Federation of America.

HANY Scholarship Awarded

Eighteen candidates are sharing \$46,000 in HANY scholarship awards this academic year.

Among the stipends given this fiscal year are the "Isabel K. Brach Award" (given to a Biomedical Science major), the "Dr. Margaret Hilgartner Award" (given to a Biology major), the "Dr. Margaret Karpatkin Award" (given to a Osteopathy Medicine major) and the "Matthew Lee Greer Children's Foundation Award" (given to a Child Psychology, Environmental Science, Civil Engineer and Business majors).

Eligibility now extends from persons with certain diagnosed bleeding disorders to carriers and unaffected children of parents with qualified bleeding disorders. *April 1, 2017 is the deadline for applying.* Call or email 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.

LadyBugs Program

The LadyBugs program is designed for women 18 and older who are mothers, caretakers, siblings and women with a bleeding disorder. The goal of our day-long program is to provide education about medical developments, advocacy skill building, stress management techniques and more to encourage women to recognize that their health is equally important.

The LadyBugs program empowers women to find their voice when it comes to decision making about the health of themselves and their loved ones.

As this is a day-long program designed to meet YOUR needs only; we ask for you to make child-care arrangements accordingly. In the event that it is impossible for you to secure childcare, it will provided on site.

Space is extremely limited as we only have resources for 35 women. Preference will be based on a first-come, first-served basis.

Meet us for registration and a continental breakfast at 9:00 am.

Where: Affinia Hotel
371 Seventh Avenue at 31st Street
New York, NY 10001

When: September 24, 2016 (Saturday) at
9:00 am - 5:00pm

Call to RSVP (212) 682-5510 or email at gabrielablum@hemophiliany.com

If you have food allergies, please email Joan at jward@comphealthed.com.

Please register with the LadyBugs program at www.ladybugsprogram.org

2016 Fall Farm Festival

The Hemophilia Association of New York invites children with bleeding disorders (17yrs & under), siblings and parents to come to the 2016 Fall Farm Festival.

You must be a registered client with HANY.

Where: White Post Farms
250 Old Country Road
Melville, NY 11572
631-351-9373
www.whitepostfarms.com

When: October 15, 2016 (Saturday) at
11pm - 4:00pm

RSVP is Required to attend this event by **October 10, 2016.**

Please contact Gabbi at (212) 682-5510 or email at gabrielablum@hemophiliany.com

2016-2017 Annual Appeal

The Association's Annual Appeal is starting. Please consider a tax-deductible donation to HANY.

Funds received will allow HANY to continue it's almost 65 year mission of support and assistance to the bleeding disorders community. Thank you

**PLEASE HELP THE
BLEEDING DISORDERS
COMMUNITY**

(A contribution form is enclosed)

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.

Please contact your treatment center for resources and information for educators and school nurses to explain hemophilia and other bleeding disorders to start the school year right.

Fall 2016 Bleeding Disorders Advocacy Network Fall Family Retreat

The dates for the BDAN Fall Family Retreat are **October 08 - 10, 2016 Columbus Day weekend**. The 2016 Theme is "Make it your own". This is the 12th year of the Fall Family Retreat.

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 email Bob Graham at bobgraham04@msn.com or 315-396-2944.

HANY's Past Events

- **August 18th**, we had a *Spa Day* for the Blood Sisterhood members.
- **August 26th**, we had a *Bowling Night* event for the Blood Brotherhood members.
- **September 8th**, we had an Educational meeting about *Planning your Future with Hemophilia* provided by Pfizer.

Blood Brotherhood & Blood Sisterhood Events

The Hemophilia Association of New York cordially invites you to be a member of the Hemophilia Federation of America's Blood Brotherhood & Blood Sisterhood events.

For more information on events & educational meetings contact HANY at 212-682-5510. To suggest a topic please email Gabbi at gabrielablum@hemophiliany.com



For 60 years, MedicAlert Foundation has provided live 24/7 emergency medical information and identification services for members and their families.

MedicAlert relays critical information to emergency responders about your important health concerns such as a bleeding disorder and other medical conditions, to ensure your safety and peace of mind.

Learn more about the importance of medical IDs, go to www.medicalert.org. If you need a Medic Alert, please talk to your social worker at any of the treatment centers to send us a request.

Two New York Students Receive Scholarships through Baxalta's Education Advantage Scholarship Program

Two students from New York are among 63 people nationwide to receive a 2016-17 academic scholarship from Baxalta, now part of Shire. 42 scholarships were renewals while 21 were new.

The *Education Advantage* scholarship program, now in its seventh year, is designed to help eligible students with a bleeding disorder offset the costs of higher education, advance their careers, and pursue their dreams. Baxalta US Inc. is providing more than \$375,000 to this year's scholarship recipients nationwide.

James Konigsberg from New York, NY is attending Georgetown University. He plans to major in political economy. In his personal statement, one requirement of the application process, James wrote, "As a Georgetown student, I feel I will gain the knowledge and experience needed to become a leader in business and to make a positive impact on the world."

Zachary Davis from Apalachin, NY is attending Broome Community College. He plans to become a nurse. In his personal statement, one requirement of the application process, Zachary wrote, "I am so excited to become a nurse. It may not be the prettiest job in the world, but I can say I will be proud of it every day."

Two additional New York residents also received renewed scholarships through the *Education Advantage* scholarship program. Through the first seven years of the program, Baxalta has awarded more than \$1.7 million in 139 merit- and financial need-based scholarships.

Program Background

The *Education Advantage* scholarship program is open to people with hemophilia A or B (factor VIII or IX deficiency), including those with inhibitors (factor VIII or IX deficiency), regardless of which brand of factor treatment they use. It is also open to students with von Willebrand disease.

The program provides financial aid for a wide variety of educational options, including four-year bachelor's degrees, associate's degrees, technical/vocational certifications, as well as the GED Test. 2016-17 scholarships were awarded up to:

- College/University — \$7,000 renewable for up to three additional years.
- Community College/Technical School: \$1,000 — renewable up to one additional year.
- GED: \$150 (one time only).

The *Education Advantage* program is supported financially by Baxalta and administered by Scholarship America®, the nation's leading independent scholarship program administrator. Scholarship America reviews all scholarship applications, determines eligibility, and selects the scholarship recipients. Baxalta has no input into the selection of recipients.

Education Advantage scholarship program applications for the 2017-18 academic year will be available online beginning in January 2017, or by calling Scholarship America at 877-544-3018.

Go to www.BaxaltaHematology.com/us/EA to learn about this year's scholarship recipients.