



# Hemophilia OUTLOOK

A Newsletter of

**The Hemophilia Association of New York, Inc.**

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❄️ **WINTER 2016 - 2017** ❄️

*Steven L. Margolies, MD Family Educational Conference*

*November 11 - 13, 2016*



**Spirit Flag**

HANY had its first weekend conference. The weekend was meant to be educational, fun and a time for our families to network. If you attended we hope it met your expectations if you presented - Thank you! Here are some of our sessions:

A welcome and keynote addressed by Pat Torrey of "GutMonkey" • Aquatic Therapy • Art Therapy • Be Prepared (a teen program) • What's in the pipeline • Tools (for pain management) • Can I get a Job? • A Women's Session and • A Couple session.

Saturday night we had dancing and networking for the families after a busy day of sessions and Mohonk activities.



**Aquatic Therapy**



**Be Prepared**

We are planning the 2017 Steven L. Margolies, MD Family Education Conference and welcome your suggestions. If you are interested in attending, contact us to ensure receipt of information when available.

## **HANY Scholarship Program**

For the 2016-2017, academic year the maximum award set by the Board of Trustees will be \$7,000, although lesser amounts may be awarded.

The program is for qualifying full-time study at an accredited college, university, graduate school, or certified trade or vocational school for the coming school year. Applicants will be judged on their achievements and financial need.

HANY scholarships are available to persons with inherited genetic bleeding disorders (as diagnosed by a board-certified hematologist) and their children.

Applicants must be registered with HANY and live within the fourteen counties of southeastern New York. Application must be postmarked by April 1, 2017

### **Applications are NOW open!!!**

For an application : Call: 212-682-5510  
Email: [gabrielablum@hemophiliany.com](mailto:gabrielablum@hemophiliany.com)

## **How Does the Election Affect You?**

It is too soon to tell. Keep in mind that since 1952 the Association has been advocating for those with bleeding disorders.

As a founding member of the New York State Bleeding Disorders Coalition, HANY will stay well informed and close to the issues if and when they arise.

Please, consider joining us for our annual New York State Advocacy Day March 19-20, 2017 in Albany.

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

## **Hemophilia Federation of America Symposium April 6 - 9, 2017**

Hemophilia Federation of America's annual educational event will be on April 6-9, 2017 in Providence, Rhode Island.

HFA awards over 100 travel scholarships to first time attendees each year for families who need financial assistance.

For more information and to register go to [www.hemophiliated.org](http://www.hemophiliated.org).

HANY will have travel assistance for attendees.

## **Hemophilia Treatment Centers**

### **New York Presbyterian**

<http://www.cornellpediatrics.com>

### **Mt. Sinai Medical Center**

[www.mountsinai.org](http://www.mountsinai.org)

### **Northwell Health (formerly LIJ)**

<http://www.northwell.edu>

### **Albany Medical Center**

[www.amc.edu](http://www.amc.edu)

### **New Comprehensive HTC**

### **Montefiore Hospital**

[www.montefiore.org](http://www.montefiore.org)

## **As The End Of The Year Approaches . . .**

Please consider support of the Hemophilia Association of New York. All donations are tax deductible and will allow HANY to continue its 65 year mission of support and advocacy for those with Bleeding Disorders

Also check out HANY's facebook page for the Charity Footprint & Amazon Smile links.

# **OPEN ENROLLMENT FOR 2017 HEALTH INSURANCE**

Here is the list of the things you need to make sure your health insurance plan covers when your open enrollment period starts. An open enrollment period is the time when individuals can enroll themselves and any dependents in Qualified Health Plans for the following year.

Open enrollment started November 1, 2016 Also, **if you'd like your plan to start on the first of January 2017, you must enroll by December 15, 2016.** Even a day late and your coverage will not begin until February 1st, 2016. Open enrollment this year ends on January 31, 2017. The first step is knowing when your open enrollment period is; the second is finding the right plan.

The Affordable Care Act (ACA) requires insurance companies to provide an easy-to-read chart of benefits for any plan it offers. This is great for the general benefit items, but for patients with chronic conditions, it is the details that count. For example, bleeding disorder patients around the country have found that their hemophilia treatment center (HTC) is in the network of providers their insurance will cover only to learn that the doctor they see at their HTC is not. In addition, many insurance companies now are limiting pharmacy choice for patients, and moving factor from major medical coverage to pharmacy coverage. This allows them to charge a percentage for the cost of factor (20-50%) versus a copay. *This is why it is essential to enrolled in your factor manufacture's copay and deductible program.*

This is not all. Though the ACA capped annual out-of-pocket costs, some patients have to pay the full out-of-pocket limit in the first month that the insurance policy is effective. For example, the out-of-pocket maximum for an individual in 2016 is \$6,850 individuals and \$13,700 for a family. Patients with chronic and expensive diseases are reaching their out-of-pocket maximums in one month and they can't afford to pay. Legislation is in the works all over the country to cap the amount that patients have to pay monthly for specialty drugs. Until legislation like this becomes law, many individuals and families are at risk for financial hardships should they reach their limit too quickly.

## **DATES TO REMEMBER:**

- **November 1, 2016** - Open enrollment begins. This is the first day you can apply for, keep, or change your coverage.
- **December 15, 2016** – Last day to enroll for new coverage effective January 1, 2017. If you want to change your plan effective January 1, you must do so by this day. This is also the date by which you must update your financial information in order to receive the correct amount of assistance from the government when your 2017 coverage begins.
- **December 31, 2016** – Coverage under 2016 health plans ends.
- **January 1, 2017** – 2017 coverage begins for those who enroll or change plans by December 15.
- **January 15, 2017** – Last day to enroll for new coverage that begins on February 1, 2017, or make changes to existing coverage to take effect on February 1.
- **January 31, 2017** – Last day to enroll in or change coverage for 2017 health plan. If you do not enroll by this date, you may be required to pay a penalty to the government.

**New York State Bleeding Disorders  
Coalition - Albany Days  
March 19-20, 2017**

Be a part of the team, sign up today!

Come join us on **March 19-20, 2017** in Albany! It's a great opportunity to have your voice heard, network with other families and learn the key issues affecting our community. This year we plan to be educating our youth with a special program.

GOAL: Educate our legislators on bleeding disorders and what the issues and needs are of our community.

If you would like to attend, please send an email to [admin@hemophiliany.com](mailto:admin@hemophiliany.com) with your name and mailing address (for hotel reservation). Your hotel, driving mileage and Amtrak will be reimbursed.

**Advocacy: Anti Mandatory Mail  
Order Reform Legislation**

The New York State Bleeding Disorders Coalition (NYSBDC) is a partnership of not-for-profit patient organizations and treatment centers dedicated to public advocacy on behalf of people affected by bleeding disorders in New York State. Together, these organizations provide a broad range of medical care, education, and support to people affected by bleeding disorders throughout the state.

The NYSBDC strongly supports passage of S.2530/A.6194. This legislation is necessary to restore the intended functioning of the Anti-Mandatory Mail Order law and ensure patients have access to medications from a qualified network local or mail order pharmacy.

The Anti Mandatory Mail Order (AMMO) law was passed in 2012 to ensure patient's could choose a qualified network local or mail order pharmacy based on which option best met the patient's needs. However, some health plans have used provisions of

the AMMO law to impose unnecessary additional terms and conditions on qualified network local pharmacies that effectively excludes them from serving patients in favor of mail order pharmacies. S.2530/A.6194 better defines terms, and remove provisions, in the AMMO law enabling these exclusionary practices by health plans. S.2530/A.6194 also holds local and mail order pharmacies to the same reimbursements for covered medications, ensuring no additional costs to patients.

NYSBDC believes patient access to a pharmacy option which best meets the patients needs is essential to maintaining patient health. For more information visit [www.nysbdcoalition.org](http://www.nysbdcoalition.org).

**Silly Science Event  
Saturday, January 28, 2017**

Incorporate some fun & simple engineering with Mini Robots and their "Systems". Our hope is for the kids to have a great appreciation for all of the "systems" in their life while dealing with a bleeding disorder.

We invite Parents & kids from **ages 8 to 14** on Saturday, January 28, 2017. Time & location to be determined. If you want to attend, please RSVP by emailing Gabbi at [gabrielablum@hemophiliany.com](mailto:gabrielablum@hemophiliany.com).

**HANY's Past Events**

- **September 24**, LadyBugs Program for the ladies of our community.
- **October 22**, Fall Farm Festival for the families.
- **November 11 - 13**, Steven L. Margolies, MD Family Educational Conference at Mohonk Mountain House, New Paltz, NY.



*Our Best Wishes for a Happy  
and Healthy New Year!*