

# Hemophilia OUTLOOK

A Newsletter of

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

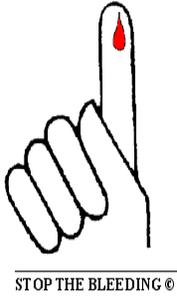
131 West 33rd Street, Suite 11D

New York, NY 10001

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

Email: hany@bestweb.net

www.hemophilia-newyork.org



 **SUMMER 2015** 

## **Memorial, Honor & Tribute Contributions**

HANY depends on voluntary contributions to provide direct services to persons with bleeding disorders and to fund medical research, which will hopefully find cures for hemophilia and related conditions. If you are planning a celebration such as a Wedding, Bar or Bat Mitzvah, Christening or even a birthday please consider a donation in lieu of flowers or favors. HANY will provide you with recognition scrolls for the day of your event.

To make a *Memorial* or *Honor & Tribute Contributions* contact HANY at 212-682-5510 or visit [www.hemophilia-newyork.org](http://www.hemophilia-newyork.org).

## **SAT Prep Course coming in the Fall**

HANY is offering free SAT prep course in the Fall 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!

## **HANY Scholarship**

Look for the announcement of our 2016-2017 scholarship application in the Fall issue of OUTLOOK.

On Tuesday July 21st, HANY is hosting a reception for our current and past scholarship recipients. Maintaining and expanding our scholarship program is one of the more enjoyable parts of the Association's work. To RSVP for this event please contact Annie at 212-682-5510.

## **Day at the Races at Belmont Racetrack**

On May 17th, HANY held our Brooklyn Division "Day at the Races". Due to support from our sponsors, HANY was able to extend admission to some of our families. It was a great time for all.

Special thanks to Kathy Hornrick our volunteer event coordinator. She did a great job!

**Si usted necesita traducción o 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.**

## **Summer Reminder**

Every summer OUTLOOK carries a reminder of ways to avoid injuries while enjoying summer activities. Most people are aware that running on a wet pool deck, wearing flip-flops during active play, and using a baseball rather than a softball can cause accidents. Everyone should wear helmets when using skateboards, skates, scooters, and bicycles.

However, it is easy to forget that amusement park rides can cause serious, even fatal, injuries. The greatest hazard on these rides is to the brain. The sharp turns common not only on roller coasters but on many rides have been known to result in bleeding beneath the brain's outer membrane ("subdural hematoma"). This must be of particular concern to people with hemophilia. Prophylaxis is a good precaution before a day at the amusement park or any strenuous activity. But it isn't a replacement for observing safety precautions.

The most recommended sports for people with bleeding disorders are those that put less impact on joints but still do a lot for muscle strength and flexibility. Swimming, walking, golf and bike riding are good suggestions. However, with proper safeguards, it's possible for people with bleeding disorders to enjoy a wide variety of outdoor activities.

You and your child can experiment together to find out which activities work the best for him/her and for your family. Talk to the HTC staff, especially the physical therapist, about appropriate activities. Other parents of children with bleeding disorders can be helpful, especially if their children are older than yours.

## **Travel Reminder**

When traveling with your clotting factor, it is advised that you bring a prescription from your physician that includes contact information, as well as a letter from your physician/Hemophilia Treatment Center providing a brief explanation of your condition and the need for this medication. In addition, if you bring needles onto an airplane in your hand luggage you must also have the clotting factor with you.

Check with your airline at least two days prior to departure to learn their specific regulations regarding the transport of medications. Each airline is developing regulations that are subject to change.

It is more advisable than ever before to carry a physician's letter that states the name of the patient, the name of the product being carried, the fact that diluent water, needles and syringes are required to infuse the product, the fact the person needs to carry the product at all times for medical reasons, and that for reasons of asepsis the product must not be open until needed.

## **National Hemophilia Foundation's Annual Meeting**

August in Dallas, Texas — that's where the National Hemophilia Foundation is headed this year for its 67<sup>th</sup> Annual Meeting. Mark your calendars and start planning now for the conference, August 13-15, 2015. You can count on interesting educational sessions, interactions with others who share similar concerns and social activities planned with you in mind. For more information on the meeting call NHF at 212-328-3700 or go to their website at [www.hemophilia.org](http://www.hemophilia.org).

## Mohonk Mountain House Men's Retreat



On May 15th-17th, HANY hosted a Men's Retreat at Mohonk Mountain House. Patrick Torrey of GutMonkey facilitated the event. Below are some comments from some of our participants:

*"As an older patient, I really appreciate the chance to spend time with my peers at a program specifically created for us. There aren't many of us, or many programs for us, so this was a wonderful opportunity."*

*"Multigenerational meetings are a good idea! Especially for this community."*

*"Nice to bond with the guys at HANY, and the seminar was very interesting. Nice point of view, self-awareness, and motivating. Thanks for putting this together, it was fantastic."*

*"It was beneficial sharing ideas & stories with people in the same circumstances."*

*"This could be the start of something really great. Seeing younger and older guys, talk, share, and bond so readily is fantastic. We can learn a lot from each other if given the chance, so I really hope HANY will have more programs like this."*

Suggestion for future retreats include a family retreat with men & women component. If you would like to be part of the planning for 2016 contact HANY at 212-682-5510.

## Camps

OUTLOOK readers know how enthusiastic — we and the parents of former campers — are about the developmental benefits camp offers to children with chronic disorders. Campers have had wonderful experiences at the three specialty camps nearest to our area, listed below. All three provide on-site medical care and supervision.

Transportation and travel arrangements to camp are the responsibility of the camper's family. HANY offers help with "camperships" and the cost of transportation for those who require it.

### **Camp High Hopes**

Where: Brantingham, NY

Website: [www.camphighhopes.org](http://www.camphighhopes.org)

Phone: 315-396-5644

### **Double "H" Ranch**

Where: Lake Luzerne, NY

Website: [www.doublehranch.org](http://www.doublehranch.org)

Phone: 518-696-5676

### **The Hole in the Wall Gang Camp**

Where: Ashford, CT

Phone: 203-772-0522

Website: [www.holeinthewallgang.org](http://www.holeinthewallgang.org)

### **Inhibitor Family Camp**

Website: [www.comphealthed.com](http://www.comphealthed.com)

Phone: 781-878-8561

To register, applicants must have an active inhibitor, or have had an active inhibitor within the past 12 months and fall between the ages of 6-18.

*East Coast Session:* October 16 - 19, 2015 at Victory Junction, NC.

## **An Evening for Bleeding**

On June 8th HANY & Believe Theatrical held their annual fundraising event to support the Hemophilia Association of New York (HANY) patient services fund & The Adam Spencer Lynch Arts & Media Scholarship.

As many of you know, Believe Theatrical (BT) co-founder Patrick James Lynch has severe hemophilia and is a member of HANY. Since 2013, Believe has produced an annual theatrical fundraiser to benefit HANY and as of 2014, part of the night's proceeds go toward a scholarship named after Patrick's late brother Adam, benefitting a college-bound person with a bleeding disorder seeking higher education in either the arts or media.

In 2013, Believe Theatrical produced an extremely well-received staged reading of BT co-founder Ryan Gielen's DELETED SCENES featuring Anthony Rapp (RENT, If/Then), Terri Conn (As The World Turns, One Life to Live), Patrick, & BT company member Katy Wright-Mead.

In 2014, Believe Theatrical produced the first professional staged-reading in NYC of John Cariani's LOVE/SICK with a 20-member cast (yup, 20!). The night included the talents of Sam Underwood (The Following, Dexter), Elizabeth A. Davis (Tony-nomination - Once), Jennifer Mudge (Into The Woods, Rocky on Broadway), Alex Wyse (Lysistrata Jones, Bare, "Modern Family") and what seemed like an endless parade of incredible actors!

And now, in 2015, Believe Theatrical presented NEVER HAVE I EVER - an evening of musical classics and pop songs sung by professionals who would otherwise never get a chance to sing these songs on a NYC stage.

The night included John Cariani, Sam Underwood, Seth Kirschner, Melissa Mitchell, Patrick James Lynch, Grace McClean, Sydney Shepherd, Aly Tadros, Michael Quadrino, and the cast from Rent (headed for Edinburgh Festival Fringe this August).

To learn more about Believe Theatrical visit [www.believetheatrical.com](http://www.believetheatrical.com).

## **HANY Thanks Our Sponsors**

### *"Day at the Races"*

Baxter  
Bayer

### *"An Evening for Bleeding"*

Bayer  
Novo Nordisk  
Biogen Idec  
Baxter  
CSL Behring  
Pfizer

## **Blood Brotherhood Events & Men with Bleeding Disorder Peer Group Meetings**

The Hemophilia Association of New York cordially invites you to attend our Blood Brotherhood events and Men with Bleeding Disorder Peer Group Meetings. For more information on events & meetings contact HANY at 212-682- 5510. To suggest a topic please visit our website.

## **Women's Peer Group Events**

The Hemophilia Association of New York cordially invites you to attend our women with bleeding disorder peer group events. If you are interested in participating in the group events, contact HANY at 212-682-5510.