

# Hemophilia OUTLOOK

A Newsletter of

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

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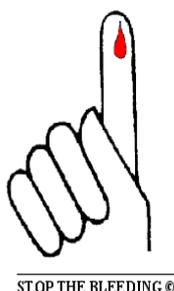
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## SPRING 2016



STOP THE BLEEDING ©

### **April 1<sup>st</sup>, Deadline for HANY Scholarship Applications**

HANY is offering scholarships up to \$7,000 for qualified individuals who are planning full-time study at a college, university, graduate or vocational school in the academic year 2016-2017.

Applicants must have, or be the child of a person who has, a genetic bleeding disorder and is registered with HANY. They must live within the 14 southeastern counties of New York State.

If you are interested, call us for an application at 212-682-5510. Remember, we must receive completed applications by April 1, 2016.

### **Other Scholarships Available**

Pfizer pharmaceutical is offering Soozie Courter hemophilia scholarships to undergraduate, graduate and vocational school students. For more information, visit [www.hemophiliavillage.com](http://www.hemophiliavillage.com).

For a full list for the various scholarship programs look at the website of LA Kelley Communication ([www.kelleycom.com](http://www.kelleycom.com)) or call HANY.

### **HANY Upcoming Events**

*May 15<sup>th</sup>* – Day at the Races at Belmont Racetrack.

*June 13<sup>th</sup>*– “An Evening for Bleeding”, a theatrical fundraiser event to support our patient services fund.

*"Raffles for Research" are being offered at \$25 a ticket or 5 for \$100. Cash prizes of \$1,000, \$800, \$600, \$400 and \$200 will be drawn at our An Evening for Bleeding fundraiser.*

*June 20<sup>th</sup>* – 9<sup>th</sup> Annual Matthew Lee Greer Golf Classic.

*November 11<sup>th</sup> – 13<sup>th</sup>* HANY Family Retreat at Mohonk Mountain House (*see page 3 for more details*).

*For more of HANY upcoming events, please visit our website at [www.hemophilia-newyork.org](http://www.hemophilia-newyork.org).*

**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.**

## **Insurance Reminder**

*Those of you who use factor, it is very important to sign up with your manufacturer's co-pay and deductible program.*

Many of these programs will pay your annual deductible and/or co-pays related to your factor order.

Listed below are the manufacturer's programs and contact information.

### ***Biogen Idec***

*Co-pay program 1-855-692-5776*

### ***Pfizer***

*RxPathways 1-866-706-2400*

*Factor Savings Card 1-888-240-9040*

### ***Baxalta***

*The Care Program 1-888-229-8379*

### ***Grifols***

*Savings Card Program 1-855-355-2574*

### ***Bayer***

*Co-pay/Coinsurance Assistance Program*

*1-800-288-8374*

### ***CSL Behring***

*Patient Assistance program*

*1-800-676-4266*

### ***NovoNordisk***

*SevenSECURE - You must create an account on the Changing Possibilities site for complete access to the SevenSECURE® program.*

### ***Patient Services Inc. (PSI)***

*Programs Assistance for Bleeding Disorders. To apply for assistance, visit PSI website at [www.patientservicesinc.org](http://www.patientservicesinc.org) or call 1-800-366-7741.*

## **Camps Fill Up Early**

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 specialty camps nearest to our area, listed below. All camps provide on-site medical care and supervision.

### ***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.

*West Coast Spring Session: April 15 - 18, 2016. This Spring's Inhibitor Family Camp program will be held at The Painted Turtle in Lake Hughes, California.*

*East Coast Session: October 7 - 10, 2016 at Victory Junction, NC.*

### ***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.doublehbranch.org](http://www.doublehbranch.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)*

## **HANY Family Retreat at Mohonk Mountain House**



HANY is having its first Family Retreat **November 11-13, 2016** (*Veteran's weekend*) at Mohonk Mountain House. Programs, meals and rooms are covered by HANY.

Invited are those with bleeding disorders. Children 17 years and under are invited with their parents including siblings. Adults are invited with their spouse or significant other.

If you and your family are interested in attending our first Family Retreat, please respond with your name, phone number, number of adults and number of children. HANY will reserve your room and follow up with further information.

*Mohonk Mountain House* is an elegant resort hotel located on the Shawangunk Ridge in Ulster County, N.Y. For more information on the resort visit: [www.mohonk.com](http://www.mohonk.com).

Rooms are limited & going fast! Rooms will be reserved on a first come first basis.

You **MUST** be a registered client of HANY. To request an application for registration, please contact HANY at 212-682-5510.

## **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 Disorders Peer Group Meetings. For more information on events & meetings contact HANY at 212-682- 5510. To suggest a topic please visit our website.

## **March Declared Bleeding Disorders Awareness Month**

*(Hemophilia.org, January 27, 2016)*

NHF announced that the US Department of Health and Human Services (HHS) has approved for inclusion on its National Health Observances calendar each March as "Bleeding Disorders Awareness Month" beginning this year.

This special month aims to foster a stronger sense of unity and shared purpose among individuals in our community with all inheritable bleeding disorders, and elevate awareness and engagement in our journey beyond our community.

"Bleeding Disorders Awareness Month," which has been included by HHS as a National Health Observance, formalizes and expands upon the designation 30 years ago of March 1986, as "Hemophilia Awareness Month" by President Ronald Reagan.

"Whether you have hemophilia, von Willebrand disease or a rare factor deficiency, you are part of close-knit, interdependent "family," the bleeding disorders community," said Val D. Bias, NHF CEO. "I am so proud of our community, my NHF team and HHS for making this month—our month—possible!"

## **National Hemophilia Foundation's (NHF) Annual Meeting**

NHF's 68<sup>th</sup> Annual Meeting will be held in Orlando, Florida at the beautiful Gaylord Palms Resort & Convention Center on **July 21-23, 2016**.

The Annual Meeting venue is just minutes away from the world famous Disney World, Magic Kingdom, Universal Studios, SeaWorld, and more! Join NHF for three days full of educational sessions, networking opportunities, and access to the exhibit hall.

All registrations include entrance to the Opening Session, Opening Reception, Awards Ceremony, and the exciting Final Night event. They even offer childcare for children under 17 years old.

Whether you're a first timer or regular attendee, NHF's annual gathering of the entire bleeding disorders community in the US offers participants three key elements: an array of educational sessions, a hands-on Exhibit Hall with fun for all ages and social events where you can unwind each day.

*\*Please note, due to the joint effort with WFH, all medical sessions will take place at the WFH World Congress this year instead.*

For more information visit website: [www.hemophilia.org](http://www.hemophilia.org) or call toll-free 800-424-2634.

## **2016 World Federation of Hemophilia (WFH) World Congress**

Taking place from **July 24 – 28, 2016** in Orlando Florida, the WFH 2016 World Congress will be held right after NHF's 68th Annual Meeting.

The NHF is particularly honored to host the largest international meeting dedicated to hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders since it is the first time in over 25 years that the global community meets in the United States. This will be a unique opportunity for U.S. healthcare providers, NHF chapters, as well as patients and their families to join the global bleeding disorders community.

In addition to the 70 concurrent sessions, covering a wide range of topics, the WFH 2016 World Congress will feature parallel plenary sessions to provide participants with new insights and valuable information for both medical and multidisciplinary interests.

Congress attendees include hematologists, pediatricians, orthopedic surgeons, physiatrists, physiotherapists, dentists, nurses, social workers, psychologists, geneticists, laboratory technicians, researchers, and scientists, who, together, represent the comprehensive care team for people with bleeding disorders.

The WFH 2016 World Congress is also the global meeting place for national patient organization leaders, as well as people with bleeding disorders and their families. Presentations, workshops, symposia, and exhibits will feature cutting-edge trends in research and treatment for hemophilia and other inherited bleeding disorders. In addition, there will be ample opportunities to network, share experiences and make new friends during engaging social events.

NHF has been committed to the WFH and the shared vision of Treatment for All for over 50 years. They will work together to ensure that the WFH 2016 World Congress is the largest and most successful in the organizations history.