HANY SCHOLARSHIP

There are 15 applicants that will receive awards through our scholarship program. This year's scholarship awards totaled $45,500.

Look for the announcement for the 2018-2019 scholarship program in the Fall issue of OUTLOOK.

PATIENT ASSISTANCE PROGRAMS

The Patient Assistance Programs are offered by your factor manufacturer. Whether you are staying on your current treatment or looking for something new, it is very important for you to understand what they have to offer.

Some manufacturer offer assistance with copays, free trials of new medication and more. If you would like the information of any of the providers, please contact us at 212-682-5510.

SECOND ANNUAL
STEVEN L. MARGOLIES, M.D.
FAMILY EDUCATIONAL CONFERENCE
NOVEMBER 10-12, 2017

The 2nd Annual Steven L. Margolies, MD Family Educational Conference will be held November 10-12 at Mohonk Mountain House.

Remember: First time attendees are given preference as rooms are limited

This educational conference is for anyone with a bleeding disorder. Children 17 years and under are invited with their parents including siblings. Adults are invited with their spouse or significant other. You MUST be a registered client with HANY.

Rooms will be reserved on a first come first basis. Programs, meals and rooms are covered by HANY.

If you are interested in attending the family educational conference, please contact us at admin@hemophilia.com

We will reserve your room and follow up with further information as event gets closer.
SAT PREP COURSE

SAT test prep can help your teen navigate this big test with ease, earning impressive scores along the way to get into the best universities, the stakes are high for preparing for college. We will reimburse you for your SAT prep course. For more information email us at admin@hemophilia.com

GENERAL, MEMORIAL & HONOR CONTRIBUTIONS

We depend on voluntary contributions to provide direct services to persons with bleeding disorders and to fund medical research, to hopefully find cures for hemophilia and related conditions. To make a contribution go to: www.hemophilia.com/index.php/donate

SAVE THE DATE
2018 HFA SYMPOSIUM

On April 6-9, 2017, nearly 1,300 members of the bleeding disorders community came together in Providence, RI.

The 2018 Hemophilia Federation of America symposium will be April 26-28 in Cleveland, Ohio. We will offer travel scholarship. If you are interested in attending please contact us after February 2018 at 212-682-5510.

Si usted necesita traducción or interpretación en español de algún articulo en estas hojas de noticias por favor de llamar a Ann Peréz o Gabriela Blum al (212)682-5510.

FRIENDLY TIP

Robert Burns wrote that the best laid schemes of mice and men oft go astray. While the technological advancements of transfer devices allow for easy storage and consistent reconstitution, on rare occasion they may not properly prepare your factor. If this happens to you, it is important to know what steps to take.

First, never discard your factor if the device misfires. More often than not, executing the troubleshooting steps provided with your factor will fix the problem. In the case it doesn’t work, keep that dose so that it can be returned and reviewed by the manufacturer for replacement.

If that does not work or troubleshooting information is not available, consult your health care provider(s). You can also reach out to the manufacturer’s local representatives who can demonstrate proper techniques and help contact customer service for replacement, if necessary.

NATIONAL HEMOPHILIA FOUNDATION
ANNUAL MEETING

The 69th National Hemophilia Foundation Annual Meeting will be held in Chicago, Illinois at the Hyatt Regency Chicago on August 24-26, 2017. For more information go to NHF’s website at www.hemophilia.org.

CAMPS

If you have registered with a camp, we can help you get there. We offers reimbursement for the cost of transportation. Transportation and travel arrangements to camp are the responsibility of the camper’s family. For more information send us an email to admin@hemophilia.com

HANY UPCOMING EVENTS

July 15: Nutritionist (Spanish Session)
July 22: Blood Brotherhood Meeting
October 1: 65th Anniversary Gala at Yankee Stadium.
November 10 – 12: Our Family Educational Conference at Mohonk Mountain House.
This Month there are two Pioneers of the Hemophilia Community we would like to acknowledge.

Chris Bombardier, the first person with Hemophilia to climb Mount Everest. An amazing feat, he is a pioneer and his efforts will make the paths of others smoother.

The second pioneer, John O’Sullivan, was a gentleman of 83 years of age, who lived his life with a severe bleeding disorder. In a very quiet way he too made the paths of his peers smoother.

His mother had been told that he would not live a long life – 16 years, was his expected lifespan. His friends thought that he was a kind of “Guru” because of his wise, peaceful and content manner. He lived by the saying “Let It Happen” – that there was no need to control life, or the outcome of events ....Just Let It Happen. Due to his hemophilia, John lived a solitary life. He spent the last couple of years in a Nursing Home when he could no longer live at home with his family and he enjoyed being part of that community.

I had the pleasure of speaking with him and he was pleased to know that he was a pioneer of the hemophilia community. He was a pioneer because in the 65 year history of the Association, he was our first client to be admitted into a Nursing Home. I will not go into the difficulties he went through to be admitted, but it happened and it worked. Because of him, others who need follow have had the path smoothed out. He passed away this Spring, but I will never forget him, his amazing endeavor, nor the sparkle in his eyes when he spoke of his life experiences.

**HANY & NYCHC INHIBITOR RETREAT**

On May 12-13, together with The New York City Hemophilia Chapter, we hosted our first joint event, an Inhibitor Retreat for New York City families.

This program was intended for individuals from the New York area who are affected by active inhibitors. The program featured important information and many activities.
Hypertension or high blood pressure is one of the age-related conditions in hemophilia that has not been explored very thoroughly. Historically, before the advent of factor products, people with hemophilia often did not survive childhood. Treatment with clotting factors significantly increased life expectancy, but then the AIDS crisis came along and devastated much of the hemophilia population, so they never reached old age. It is only more recently, now that life expectancy is approximately that of the general population, that it has become possible to study aging in people with hemophilia. High blood pressure is a concern because it is associated with heart disease, stroke, eye disease and kidney disease. It is also one of the major risk factors in intracranial hemorrhage (ICH), which is 20 to 50 times more common in people with hemophilia than in the general population and can be fatal.

Hemophilia patients tend to have higher blood pressures for unknown reasons. A recent study from three U.S. hemophilia treatment centers (Barnes et al, Int J Hypertension, Epub 2014201, Nov 14, 2016) has shown that the usual cardiovascular risk factors do not explain the greater incidence of high blood pressure in people with hemophilia compared to the general population. The researchers compared 469 male hemophilia patients, both As and Bs, to age-matched male controls from the National Health and Nutrition Examination Survey, a series of surveys to evaluate the health status of the U.S. population.

Risk factors for high blood pressure in the general population include age, obesity, cholesterol, kidney function, diabetes, smoking, hepatitis C virus infection (HCV) and race. The hemophilia patients in the study showed both higher systolic (top number) and diastolic pressures (bottom number) than the general population regardless of the risk factor examined, except HCV. HCV did appear to be a risk factor for the older age group (≥ 30 years), but it only explains part of the variation. Even comparing patients being treated with blood pressure medication, treated people with hemophilia had higher pressures. The hemophilia patients in the study actually had fewer risk factors than the controls: their weights and cholesterol were lower, they had better kidney function and they had lower rates of smoking and diabetes, yet their blood pressures were worse.

Note that this does not mean that people with hemophilia can ignore the risk factors. They will still affect their blood pressure. It’s just that there is apparently more going on for hemophilia patients than just those risk factors. Something else is also causing their blood pressures to increase.

One interesting clue from the study is that there is not as much of a drop from systolic to diastolic pressure in people with hemophilia as there is in the controls. This suggests a greater stiffness of the blood vessel walls, which may indicate vascular changes occurring in hemophilia. Other studies have also identified vascular abnormalities in people with hemophilia, but overall little is known. Another unexpected finding was that the youngest age group (< 30 years) of hemophilia patients had markedly higher blood pressures than their age-matched controls. This is a worrisome result that warrants further investigation.

This study has uncovered some significant information about high blood pressure and hemophilia, but much more remains to be learned. Meanwhile, all hemophilia patients, even younger ones, should pay attention to their blood pressure. High blood pressure is known as a silent killer because there are usually no apparent symptoms until it is too late. The only way to tell if you have high blood pressure is to measure it. Normal blood pressure is 120/80 when sitting quietly. If either or both numbers are much higher, you should consult your physician about possible treatment.
The Hemophilia Association of New York is celebrating 65 years of service to the Bleeding Disorder Community on

Sunday, October 1st, 2017

Join us for a Yankee vs. Toronto Blue Jays Game
plus Gourmet food at a Private Luxury Suite

For ticket information, call us at 212-682-5510
Send us an email admin@hemophiliany.com

DAY AT THE RACES

On May 21st, HANY held "Day at the Races" at Belmont Racetrack. A special thanks to Kathy Hornreich our volunteer event coordinator and our new Staff Associate, Jessica Blanco. Great job!!!

A Special Thanks to Our Sponsors For Their Generous Support!
Shire, Bayer HealthCare, Bioverativ, Octapharma, Aptevo & CSL Behring
HANY's RESOURCE CENTER

MISSION STATEMENT
The mission of the Hemophilia Association of New York is to provide information, education, advocacy and direct assistance to and on behalf of people with bleeding disorders, and to encourage and support scientific research to improve medical treatments and develop cures for hemophilia and related disorders.

About this Newsletter
The Hemophilia Outlook has been around since 1952. It's produced quarterly and distributed to all the members of the bleeding disorder community.

We have an electronic version on our website. If you prefer not to receive a copy, please let us know.

HANY does not release any personal information without your consent.

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Resources Information
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800-230-9797
www.hemophiliafed.org

National Hemophilia Foundation
800-42-HANDI
www.hemophilia.org

Coalition for Hemophilia B
212-520-8272
www.coalitionforhemophilia.org

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UPCOMING EVENTS

July 15
Sesion en Español de Nutricion mas una clase de cocina

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Nutritionist Spanish Session plus cooking class

July 22
Blood Brotherhood Nutritionist session plus a "Cooking Classes"

August 24-26
NHF's 69th Annual Meeting in Chicago, Illinois. For more information go to www.hemophilia.org

October 1
HANY's 65th Anniversary Gala at Yankee Stadium

November 10-12
Family Educational Conference at Mohonk

HEALTH-RELATED MATERIAL IN THIS NEWSLETTER IS PRESENTED FOR INFORMATIONAL PURPOSES ONLY. THE HEMOPHILIA ASSOCIATION OF NEW YORK (HANY) DOES NOT ENGAGE IN THE PRACTICE OF MEDICINE, NOR RECOMMEND SPECIFIC TREATMENTS OR DRUGS. YOU ARE URGED TO CONSULT YOUR PHYSICIAN OR LOCAL TREATMENT CENTER BEFORE PURSUING ANY COURSE OF TREATMENT. HANY DOES NOT ENGAGE IN THE PRACTICE OF LAW. SPECIFIC LEGAL ISSUES SHOULD BE DISCUSSED WITH A QUALIFIED ATTORNEY.