



Hemophilia OUTLOOK Newsletter

The Hemophilia Association of New York, Inc.

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 **FALL 2019** 

In Memory of Dr. Robert Barish



The Hemophilia Association, Board of Trustees, and Staff, mourn the recent passing of Dr. Robert Barish. Dr. Barish was a Trustee of the Association for over 30 years. His impact and guidance were valued and will be missed.

A Memorial is being planned by his family. Contact HANY for more information.



HEMOPHILIA ASSOCIATION OF NEW YORK
PRESENTS

ADDRESSING GENDER BIAS IN BLEEDING DISORDERS HEALTHCARE: A TOOL FOR CHANGE

A training seminar that addresses the bias women experience in the healthcare world.

*Hosted by the Hemophilia Association of NY
and facilitated by Christine VanHorne,
M.ED. MPH, of CVH Consulting*

When: 6:00 PM Friday, October 18 to 4:30 PM Saturday, October 19

Venue: Hotel Pennsylvania

401 7th Ave New York, NY 10001

Presenter: Christie Van Horne, M. Ed, MPH of CVH Consulting

To register: genderbiashany.eventbrite.com

or contact: 212-682-5510 | tconstantine@hemophiliany.com

Celebrating 67 Years of Service to the Bleeding Disorders Community!

On Sunday, July 21 the Association celebrated our 67th Anniversary at a Kansas City Royals vs. Yankees game at Yankee Stadium. The Blood Brothers group participated in a physical therapy program led by Dr. Michael Zolotnisky prior to the game. All attendees enjoyed beautiful weather and ball park food.

We are grateful for all of our sponsors

Takeda

Novo

CSL

Kedrion

The Hemophilia Association of NY will be hosting our first Women's Symposium, a training facilitated by Christie VanHorne, M.Ed, MPH that addresses the bias women experience through education, skills-based practice, and planning. Participants will leave this training with the knowledge and ability to be better self-advocates in a medical system that is structured to leave women behind.

*We are grateful for the support of
Takeda, Pfizer, Sanofi Genzyme, Bayer, Novo &
Grifols*

The Federal Government has reversed their position on Adjustors for 2020

In April CMS stated that beginning with the 2020 plan year it would allow accumulators adjustment programs only when used for a brand name drug where there is no generic equivalent (such is the case with Factor products). This would have presented insurers from not applying.

Manufacturers co pay and deductible assistance funds toward the insured deductible and then seeking the deductible from the insured. This was wonderful until August 26, 2019, when CMS reversed their position. For the 2020 Plan Year some insurers can refuse to count manufactures co pay and deductible assistance toward insured co pay and deductible, leaving many with large debt for their much needed factor. Hemophilia Federation of America will be doing some outreach during open enrollment to assist those who may have a choice on how to avoid accumulators.

On Time Can Be Too Late

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By: Michael Joshua

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical

attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school

to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

When Donating Factor

©LA Kelley Communications, Inc.
By: Laurie Kelley

"I only want to help..."

It's disturbing when we see the photo of an impoverished African child with hemophilia who is in pain or has chronic joint damage. And we feel helpless when we get a Facebook request for factor from a desperate young man with hemophilia in Asia. As patients, we can feel their pain. As parents of children with bleeding disorders, we want to alleviate their suffering. Yet in our desire to do good, we may end up doing something not so good. We may send factor, on our own, to a place we've never visited, to people we don't know. But won't our generosity help them? What could be wrong with that?

Plenty. In our efforts to help, we may make several serious mistakes. Here's what to look for if you receive an international request for help.

Is the request for real?

This is your first question. Just because someone says he has hemophilia and needs factor, this doesn't mean he actually does. At Project SHARE, we do extensive background checks with the local physicians and hemophilia organization (if there is one) to verify the need. And even if the request is valid, don't forget that English is not the first language in most developing countries; it's easy to get request mix-ups, dosage errors, even incorrect diagnoses.

SHARE keeps reference files on every one of the hundreds we have helped. We must be sure we have valid and accurate information. If you are approached, always realize that there may be missing information, so ask questions. We always ask for diagnosis, physician's name and contact info, whether the patient knows how to self-infuse, and how far he lives from an HTC, for starters.

Should a private citizen ship factor?

Factor is a biological drug that requires careful shipping and handling. It's expensive to ship and must travel via international carrier, such as FedEx. Factor can't be left on trucks, on planes, or in warehouses. And addresses can be tricky overseas! In India, for example, one of my favorite addresses is "Next to Camel Lot, behind Cinema."

Are you familiar with the country's customs laws? Who will pay the duties, or the tax on the shipment? It may even be illegal for you to ship these products; do you know the penalties for shipping a prescription drug over international borders? If you are employed by a hemophilia organization or HTC, are you putting that entity at risk? Whether you're a private citizen or employed by a healthcare agency, if you are unsure about duties, penalties, and costs, don't take the risk—don't ship.

What if the person is asking to come to the States for treatment?

Just say no. Most medical problems related to

bleeding disorders can be handled locally, in the country's capital. India and Pakistan, for example, have some of the best hematologists on earth. The biggest obstacle to care is often not the lack of doctors or expertise, but the lack of factor. At Project SHARE, we've found that many requests to come to the States are not for treatment but for job opportunities, college, or the chance to join relatives, either legally or illegally. Hemophilia is a ticket to get in. Be careful!

“It's an emergency!”

Emergencies are hard to fix. Often, by the time Project SHARE ships factor, the emergency has passed—for better or worse. Declaring an emergency is sometimes a way for a patient, HTC, or hemophilia organization to acquire donated factor; whether it will be used for the emergency remains to be seen. We must assess the nature of the emergency to see whether a shipment will even help. If it's surgery that can wait five days, then we can ship. Once, we saw a devastating photo of a baby in ICU with a head bleed...and we knew no factor shipment was going to help. We declined.

Check locally first.

All requests should first be vetted through the local and/or national hemophilia organization in a country. India has more than 65 chapters, so local is best. By contrast, the Dominican Republic has only one national organization. You can hop online and check the World Federation of Hemophilia's website (www.wfh.org) to get the name and email of a national organization. But with over 100 member countries, this can be time-consuming and may not produce all the info you need. Not speaking the patient's local language may make it hard to communicate! At Project SHARE, we've found that we can resolve a lot of questions by informing the local organizations, whose staff often speak English, about requests that are coming from their members directly to the United States. Our goal is never primarily to “rescue” a patient, but to turn the request back to the

national organization, to allow it a chance to help, and to strengthen its ability to solve problems.

Social media like Facebook creates connections between the developed and developing world. At SHARE we've seen many requests for factor and medical help come through Facebook to nice—but often inexperienced—hemophilia families and organizations who want to help. Americans are generous but aren't always familiar with the international world. Be careful. Don't risk losing a shipment of factor. Don't weaken the local or national groups by training patients to come to you first instead of to the national organizations. Don't be duped by people who end up getting the lion's share of donated factor because they know how to use Facebook and email—people who pump out simultaneous requests to many developed countries and organizations.

What can you do that will really help?

Contact Project SHARE. We have been working with more than 65 countries for 17 years, and we've shipped over 144 million IU of factor. We've seen and heard just about every scenario, and we can make decisions about factor that will give help where it's most needed, strengthen the national or local hemophilia organizations, and ensure that factor goes to patients with bleeding disorders. Consider us your US experts on hemophilia international aid. Like you, we want to help. Let us help you give help, effectively and efficiently.

PATIENT CO-PAY ASSISTANCE PROGRAMS

Patient assistance programs are offered by medicine manufacturers. These programs offer assistance with co-pays and deductibles. If you would like information about these programs, please contact your hemophilia treatment center or HANY at 212-682-5510.

IT IS MANDATORY TO REGISTER EVERY YEAR FOR YOUR SPECIFIC ASSISTANCE PROGRAM

PAST EVENTS



The HANY scholarship ceremony was held on July 23, 2019 at HANY's main office. There were light refreshments and comradery with Association Trustees, Staff, and past and present scholarship recipients.

A total of 13 applicants received awards through our scholarship program this year. This year's scholarship awards were close to \$50,000.

For information about the upcoming 2020 scholarship please look out for the winter newsletter.

Blood Brotherhood



On September 13, 2019 our Blood Brothers got together for a session on Cannabis, Chronic Pain & Caveats for those with Bleeding Disorders led by Ellen Kachalsky, LCSW. They ended with an exciting night of bowling at Bowlmor Lanes in New York City.

UPCOMING EVENTS



BEST OF YOU

YOUR JOURNEY TO HEALTHIER JOINTS

Hemophilia Federation of America & Member Organization Joint Health Challenge

Have you wanted to become more active, but just aren't sure how to get started? Or are you currently active and enjoy competition?

Either way, **Your Journey to Healthier Joints** is for you!



- 10-week Team Activity Challenge
- Open to Men, age 18+ with vWD, Hemophilia A or B

October 14–December 20, 2019

Register and Join HANY's Team!

Complete the Joint Health Modules on HFA's Learning Central
Wear an Activity Tracker Throughout the 10 Weeks
Engage in Physical Activity: Walking, Running, Cycling, Swimming, etc.
Support your Team!

What You Will Receive

- A Garmin vivofit 4 Fitness Tracker
- Online Support to Build a Personal Fitness Routine



The Winning Team will Present their Results at HFA's Symposium in Baltimore, in May 2020!



For more information, contact Tyshawn Constantine - 212-682-5510
tconstantine@hemophiliany.com

For more information contact Tyshawn Constantine 212-682-5510 or tconstantine@hemophiliany.com

LATINO EDUCATION SUMMIT

Look for the Descifrando los Seguros Médicos (Deciphering Insurance) presentation to be given at the October 20, 2019 New York City Hemophilia Chapter's Latino Education Summit. Julia Martin Alvarez will deliver the presentation. She will be assisted by Linda Mugford, Executive Director of Hemophilia Association of New York. It is hoped that the Latino community members attending will leave more comfortable with Insurance terms and programs.

4th Annual Steven L. Margolies Family Educational Conference



The 4th Annual Steven L. Margolies Family Educational Conference will be Dec 13 -15, 2019. We will kick the weekend off with our very own "HANY's Got Talent"! Musicians, comedians, magicians, dancers, etc. come prepared because the show will begin on Friday night after dinner. We will have instruments (guitar, keyboard, and microphone) sound systems, and projection (if needed). We will also have karaoke/instrumental versions of the songs you will sing. Notify tconstantine@hemophiliany.com | 212 - 682-5510 with your acts/ song list by November 1st.

Please keep song selections child friendly
Note: This will also be Ugly Sweater Weekend at Mohonk

We are looking forward to your showing us your Talent!

SUPPORT THE ANNUAL APPEAL

MAKE A DONATION

Your donations, no matter the amount, are so very necessary to allow the Hemophilia Association of New York to continue its decade's long assistance to those with bleeding disorders. With your help, HANY can continue the tradition of saying 'yes' when a person with a bleeding disorder comes to us for assistance. Any amount, however small, can help HANY continue to successfully provide people with bleeding disorders the help and assistance they need.

Send your tax deductible donation check to:
Hemophilia Association of New York
 131 W 33rd St Suite 11D
 New York, NY 10001
 For credit card donations please go to
www.hemophiliany.com/donate

HANY UPCOMING EVENTS

October 18 & 19 – Addressing Gender Bias in Bleeding Disorders Healthcare: Women's Health Seminar

October 20 – NYCHC Latino Education Summit: HANY presentation: Descifrando los Seguros Medicos

December 13 -15 -- Steven L. Margolies, MD Family Retreat at Mohonk Mountain House

April 3 -5, 2020 – S.A.I.L 2nd Annual Self Advocacy, Independence & Leadership) Training at Camp Quinipet at Shelter Island, NY with Guttmonkey (Ages 13-18)

SAVE THE DATE

New name, stronger commitment.

Over the years, Baxalta and Shire have provided products and services that have stayed in step with the changing needs of the bleeding disorders community. And now as Takeda, we are committed to building on that legacy. We've got a new name, but our commitment to you is stronger than ever.

Alex Hemophilia A Massachusetts
bleedingdisorders.com

Takeda Baxalta and Shire are now part of Takeda

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Young Adults and Insurance

Considerations When Deciding on a Health Coverage Plan



For more information, visit b2byourvoice.com to download *Young Adults and Hemophilia B*.

This content is brought to you by Pfizer.

For young adults with hemophilia, having insurance is a crucial step in becoming independent; the annual costs of treating hemophilia can make access to health care coverage a necessity.¹ Appropriate health insurance can be provided through an employer and is an important factor to consider during a job search, but there are other options to explore for purchasing insurance outside of employment as well.

Timing can be key: There may be a waiting period before a recently hired employee is covered under a new policy, or there may be open-enrollment dates to keep in mind for other health insurance options.

Questions to Ask About Health Insurance Plans

When deciding on a health care plan, here are some of the important points to consider, as well as the definitions of some key terms in understanding health insurance.

What are the plan's exclusions and/or limitations? *Exclusions are health care services for which your health insurance or plan doesn't pay.*²

Is clotting factor covered?

Does the plan offer product choices for clotting factor?

Does the plan cover visits to your primary care provider and your hemophilia treatment center?

Are referrals required, and if so, for which services? *A referral is a written order from your primary care doctor for you to see a specialist or get certain medical services.*²

Is there a lifetime or yearly limit or cap? *A limit or cap is the maximum benefit paid by the insurer; some insurance companies have caps on certain costs.*

What are out-of-pocket costs for the in-network providers versus the out-of-network providers? *Out-of-pocket costs are your expenses for medical care that aren't reimbursed by*

*insurance. Out-of-pocket costs include deductibles, coinsurance, and co-pays for covered services, plus all costs for services that aren't covered.*²

What is the annual deductible for in-network providers versus out-of-network providers? *A deductible is the amount you pay for covered health care services before your insurance plan starts to pay.*²

How much is the monthly premium? *A premium is the amount paid for the insurance coverage.*²

"It is important for [young adults], especially those with a chronic condition, to realize the necessity of having health insurance, as well as knowing what it takes to maintain that insurance."

— Joy Mahurin

Reimbursement Specialist

Maintaining Health Insurance

People living with hemophilia should keep in mind the potential for a lapse or gap in health insurance. In most cases, young adults may stay on their parents' policies until age 26.³ However, it's important to be aware of the potential for a lapse in coverage after age 26 and prior to having a policy of one's own through an employer or the Health Insurance Marketplace. One option to retain medical coverage is Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage. Other options may be state-sponsored individual Health Insurance Portability and Accountability Act (HIPAA) insurance plans and even Medicaid (for those who are disabled or who meet income requirements). In addition, for those who struggle to keep up with health care costs, some National Hemophilia Foundation (NHF) chapters have programs that can assist with paying deductibles, co-pays, and premiums.

References: 1. Chen SL. Economic costs of hemophilia and the impact of prophylactic treatment on patient management. *Am J Manag Care.* 2016;22(suppl 5):S126-S133. 2. US Centers for Medicare & Medicaid Services. Glossary. Healthcare.gov Web site. <https://www.healthcare.gov/glossary/>. Accessed March 28, 2019. 3. US Department of Health & Human Services. Young adult coverage. HHS.gov Web site. <https://www.hhs.gov/healthcare/about-the-aca/young-adult-coverage/index.html>. Accessed March 28, 2019.



Patient Affairs Liaisons are Pfizer hemophilia employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophilivillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).



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 is produced quarterly and distributed to all the members of the bleeding disorder community.

Electronic versions of our newsletters are available on our website.

HANY does not release any personal information without consent.

HANY's Contacts

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of.newyork

Resources Information **Hemophilia Federation of America**

800-230-9797
www.hemophiliafed.org

National Hemophilia Foundation

800-42-HANDI
www.hemophilia.org

Coalition for Hemophilia B

212-520-8272
www.coalitionforhemophiliab.org

HEMOPHILIA TREATMENT CENTERS

New York Presbyterian
www.cornellpediatrics.com

Mt. Sinai Medical Center
www.mountsinai.org

Northwell Health (formerly LIJ)
www.northwell.edu

Albany Medical Center
www.amc.edu

New Comprehensive HTC
Montefiore Hospital
www.montefiore.org