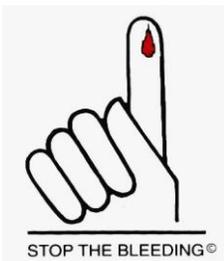


Hemophilia OUTLOOK



FALL 2017 Newsletter

There have been some changes at the Association office. Gabriela Blum, Program Director and her husband relocated to Florida in June. We wish her happiness and success in their new abode. It is with pleasure that we introduce and welcome our two new Association staff members: Jessica Blanco, joined the Association in July as Staff Associate. She will be the contact person for the office. Tyshawn Constantine joined the Association as Program Director in August. He will be working in program development and direct client services.

HANY SCHOLARSHIP

There were a total of 15 applicants who received an award through our scholarship program for the year of 2017. Awards totaling \$45,500 were dispersed amongst all applicants for their school tuition.

In order to qualify for the 2018 scholarship program, applicants must have, or be the child of a person who has a genetic bleeding disorder and is registered with HANY. Applicants must also live within the 14 southeastern counties of New York State.

All completed applications should be submitted by April 30, 2018. For an application contact 212-682-5510 or email admin@hemophilianny.com.

PATIENT ASSISTANCE PROGRAMS

The patient assistance programs are offered by factor manufacturers. Some manufacturers offer assistance with co-pays, free clinical trials and more. If you would like

information about providers, please contact 212-682-5510.

YOU MUST REGISTER EVERY YEAR

**The Hemophilia Association Celebrates
65 Years of Service to the Bleeding
Disorder Community**



Thank you to all of our attendees and sponsors



AFFORDABLE CARE ACT THREATENED!

House Republicans narrowly passed the American Healthcare Act (AHCA), their replacement for the Affordable Care Act (ACA). AHCA allows states to apply for federal waivers to avoid many of ACA's regulations. Although it keeps the preexisting condition mandate of ACA, AHCA allows insurers to charge people with preexisting conditions several times more for an insurance policy, and also to deny coverage for medications for preexisting conditions effectively excluding them from coverage. AHCA also imposes massive long-term cuts to Medicaid and reduces insurance subsidies to low-income individuals: tens of millions of people would lose health insurance. The bill has moved to the Senate, which was expected to write a more moderate version of the House bill, but



instead made several significant alterations, including deeper cuts and structural changes to Medicaid, a program that insures one in five Americans. Why this matters: People with chronic health conditions finally achieved many long-awaited protections under ACA: these are now at risk under the GOP health plan.

For info: www.cbo.gov/publication/52486



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.

Reminder: 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 serve basis. Programs, meals and rooms are

included. Transportation is not included. If you are interested in attending the Family Educational Conference, please contact us at admin@hemophiliany.com

We will reserve your room and follow up with registration documents. Some of our presenters for the conference are:

Chris Bombardier of Gutmonkey
Donnie Akers, Esq
Donna DiMichele, MD
Michael Zolotnisky, Physical Therapist
Patrick Lynch of Powering Through & Stop the Bleeding

DRIVEN BY HOPE

October 4, 2017

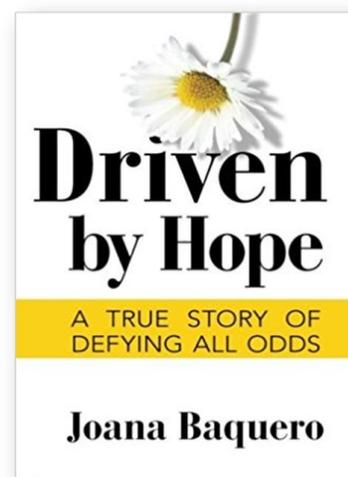
Time: 7-9 pm

Location: HANY Main Office
131 West 33rd Street, Suite 11D
New York, NY 10001

-Kindly RSVP by September 27, 2017-
tconstantine@hemophiliany.com

Join us for an inspirational talk given by the author of *Driven by Hope* (Joana Baquero).

The focus will be on self-advocacy and each attendee will receive an autographed copy of her book.



SAVE THE DATE
2018 HFA SYMPOSIUM



The 2018 Hemophilia Federation of America symposium will be held on April 26-28 in Cleveland, Ohio. HANY will be offering travel scholarships.

If you are interested in attending please contact us after February 2018 at 212-682-5510.

HFA also has first time attendee scholarships available. We encourage you to register with HFA.

HANY UPCOMING EVENTS

October 1: Blood Brotherhood Celebrates the 65th Anniversary Gala at Yankee Stadium

October 4: Driven by Hope By: Joana Baquero

October 14: Fall Farm Festival “Pumpkin Picking”

November 10 – 12: Family Educational Conference at Mohonk Mountain House

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.hemophiliany.com/index.php/donate

HEMOCRAFT



Hemocraft was created in partnership with the entrepreneurial gaming studio at Drexel University and representatives of the hemophilia community. This game aims to help younger individuals with hemophilia, 8-16 years of age, learn the importance of integrating treatment into their routine in an educational and fun gaming environment.

In Hemocraft players go on a quest and interact with the village doctor- a fictional health care professional character- to learn how to stick to their treatment plan, stay prepared, and understand how treatment works. Throughout the game, players are challenged to monitor factor levels and self-infuse to help control bleeding.



The app is available for android & ios devices. To download, go to your app store and search for Hemocraft.

LETTUCE PILLS IMPROVES IMMUNE TOLERANCE TO FACTOR THERAPY

By: Elie Dolgin



Continuing to take factor-replacement therapies can result in life-threatening allergic reactions, such as anaphylaxis. The problem is even worse with hemophilia A, a disease that is four times more common than hemophilia B and in which the missing link in the coagulation chain is a protein called factor VIII. Around 30% of people with hemophilia A develop antibodies against replacement factor VIII. Therapies are available to eliminate these antibodies. Some people undergo an intensive treatment called immune tolerance induction therapy, which involves regular intravenous administration of coagulation factors. But this is time consuming and costly (around \$1 million for an average five-year-old patient), and the treatment works in only about three-quarters of patients.

There is now prospect of a new and modern oral remedy that will prevent complications related to hemophilia therapy. Researchers have now successfully introduced Lettuce pills into the hemophilia community. The green powder used to create the green pills derives from concentrated freeze-dried lettuce-leaf cells. Each pill contains around 10,000 chloroplasts, which are the organelles responsible for photosynthesis that have been genetically engineered to produce factor IX. These proteins cannot themselves be used to prevent bleeding episodes, because the cellular machinery found in plants cannot package the human clotting factors into the biologically active form. What they can do, however, is prevent the immune system from

mounting an attack against subsequent therapy.

Dr. Herzog, in collaboration with University of Pennsylvania researchers, have proven that ingesting protein laced lettuce leaves significantly reduces inhibitor formation and severe allergic reaction to current factor therapy. With this new found information the idea to create a lettuce pill came into fruition. The researchers behind the bioengineered lettuce pill were able to prove that inhibitor formation and severe allergic reactions can be prevented in mice by feeding them with a product based on lettuce protein, which could also have the same outcome in humans.

With the prospect of an oral remedy to prevent complications related to hemophilia therapy, this garden fresh method being developed within UF laboratories has garnered much attention. As the next generations of immune-tolerant gene delivery vehicles are developed and methods to induce immune tolerance are determined, and as future therapies are further investigated the research being conducted at the University of Florida has generated a green light for a brighter future. The lettuce pill has the potential to form the basis of new product that can protect against the immune responses associated with hemophilia treatment.

References:

<https://www.scientificamerican.com/article/lettuce-pills-you-heard-that-right-may-help-treat-haemophilia/>

http://www.nature.com/nature/journal/v515/n7528_supp/full/515S166a.html?foxtrotcallback=true

HEMOPHILIA FEDERATION OF AMERICA- HELPING HANDS

On January 4, 2016 HFA included inhibitors to their well-established Helping Hands Program which includes:

Emergency Assistance: Supports families with urgent funding for basic living expenses such as housing, transportation, and utility bills

Items Reimbursement: Reimburses individuals with the cost of durable medical equipment and other medically necessary items.

Inhibitor Support: Supports families affected by inhibitors with the cost of tutoring/ educational supplies.

Financial Resources: Provides assistance for those in the bleeding disorder community who are uninsured, under insured or experiencing lapses in insurance coverage. It also offers assistance to help families facing financial strain get to access to factor product.

Resources: Hemophilia Federation of America: Programs and Services-Helping Hands/.

ANNOUNCING HFA'S INAUGURAL YOUNG ADULT ADVOCACY SUMMIT: FALL 2017

HFA has the capacity for 15-20 young adults with diagnosed bleeding disorders and other chronic disorders to attend the Young Adult Advocacy Summit. Registration will close once we reach capacity. All travel, lodging and programming fees will be covered for the selected participants.

Activities will include:

- Intensive advocacy training on how larger policy issues affect the patient community at large, including people with bleeding disorders
- Intensive communications training about how the stories of the bleeding disorders community fit in the broader patient narrative

- Coalition-Building training
- State and local advocacy training
- Sharing stories and challenges with other young adults living chronic disorders
- Building networks across multiple patient advocacy groups to benefit activism at the local level
- Congressional Hill meetings to practice skills

Want to attend?

Register on HFA's website, www.hemophiliafed.org/programs/youngadults. Be sure to follow HFA on Facebook, Twitter, and Instagram for news and updates. For more information, contact Sarah Shinkman, Advocacy and Outreach Manager, at s.shinkman@hemophiliafed.org.

We are seeking your thoughts on networking events and educational topics. Our focus in 2017 and 2018 will be to expand on our Blood Sisterhood & Blood Brotherhood programs and family events out of the New York metro area.

*Please contact
Tconstantine@hemophiliany.com with your
input.*

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 in our website. If you prefer not to receive a copy please let us know.

HANY does not release any personal information without your consent.

HANY's Contacts

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Tyshawn Constantine, Program Director
Tconstantine@hemophiliany.com

Jessica Blanco, Staff Associate
Admin@admin@hemophiliany.com

Website:
www.hemophiliany.com

Facebook:
www.facebook.com/hemophilia.association.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 Association of New York
131 West 33rd Street, Suite 11D, New York, NY 10001
Phone: 212-682-5510 • Fax: 212-983-1114
admin@hemophiliany.com • www.hemophiliany.com

UPCOMING EVENTS

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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.