Highlights of the Second Annual Steven L. Margolies, MD Family Educational Conference
November 10 - 12, 2017

The weekend was full of educational sessions, fun, delicious meals; all surrounded by pristine forest and held at a great venue. A special thank you to all of the families and speakers who helped to make this event a great success! Here is a list of some of our interactive and informative sessions: Aquatic Therapy, WOWKAPOW By: GutMonkey, Art Therapy, Women: Coping with the Challenges of Diagnosis, The Sippet Study: An International Study on Inhibitors in Hemophilia A, Infusion Support for Caregivers of Patients with Hemophilia, “Standard of Care” and “Informed Consent”, The Big 50!, Your NIH: Working to Solve the Inhibitor Problem and Cure Hemophilia, Infusion Break Out, Powering Through and “Stop the Bleeding”.

The presentation was on the innovation and remaining challenges left with getting to the cure of hemophilia with gene therapy. There is still uncertainty, and new dilemmas posed by novel options for the clinical care of persons with hemophilia (PWH), with a focus on Prophylaxis and Inhibitors.

Speed Bumps on the Innovation Highway
Her Final Take Away Points

A Hemophilia cure is becoming closer to becoming a therapeutic reality. The pace of innovation in hemophilia-related therapeutic products and preventative strategies has been impressive, leaving people with hemophilia and treaters struggling at times immunogenicity require a priority, global, and directive team science approach to solve it now.

SAVE THE DATE
NHLBI/DBDR FVIII Inhibitor State of the Science Workshop
Researchers will be discussing ways to solicit the hemophilia community into the development of a coordinated US-based blueprint for future basic, translation and clinical research focused on FVIII immunogenicity and FVIII inhibitor prevention/eradication.

When
May 15, 2018
Where
NIH Natcher Conference Center
Bethesda, MD
If you are interested in attending contact
admin@hemophiliany.com
“Mohonk’s Setting Can’t Be Topped!” - Donnie Akers

“My Daughter Got To Spend Time with Other Kids with the Same Issues She Deals With” - Unknown

“Thank You for What You Do and Thank You for Being There For Us” - Yamin Pavri
“This Was Life Changing For Me! A Real Blessing” - Amber Sidor

“We Just Want To Thank You For An Amazing Weekend. We Are So Happy To Be A Part Of The Bleeding Disorders Community. You All Went Above And Beyond to Make This Weekend Special” - Julia Ramirez

“I Was Blown Away By The Whole Experience Of The Weekend! I Met Some Great People And Learned So Much Already!” - Jackie Heney
HANY SCHOLARSHIP

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

2018 SCHOLARSHIP APPLICATIONS ARE NOW AVAILABLE!

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.

APPLICATIONS ARE NOW AVAILABLE!

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

PATIENT ASSISTANCE PROGRAMS

The patient assistance programs are offered by factor manufacturers. Manufacturers offer assistance with co-pays and deductible assistance programs. If you would like information about these programs, please contact 212-682-5510.

YOU MUST REGISTER EVERY YEAR

SAVE THE DATE
2018 HFA SYMPOSIUM

The 2018 Hemophilia Federation of America symposium will be April 26-28 in Cleveland, Ohio. We will offer assistance with travel. If you are interested in attending please contact us after February 2018 at 212.682.5510 or visit hemophiliafed.org.

Those who are registered with HFA are also eligible for first time attendee scholarships. Registration closes April 2, 2018.

PAST EVENTS

October 1- Yankees 65th Anniversary
On October 1st the Association celebrated their 65th year of serving the bleeding disorders community by having a fundraiser at Yankee Stadium. About 100 attendees enjoyed the Yankees VS. Toronto Blue Jays game in a private luxury suite with stadium and indoor seating and not the average ballpark food. HFA sponsored a Kinesio Taping program for our Blood Brothers in attendance. Although the Yankees lost- the general feeling was that we were all winners. The funds raised at the “Gala” will directly support HANY’s Patient Services which provides direct assistance to those with bleeding disorders.

Thank you to all of our attendees and sponsors
October 4 - Driven By Hope
On October 4th the Association welcomed the author of Driven by Hope Joana Baquero to her first book reading and book signing. It was an encouraging and positive reflection on her personal experience and struggles living with a rare bleeding disorder.

Driven by Hope
A TRUE STORY OF DEFEATING ALL ODDS
Joana Baquero

October 14 - White Post Farms Fall Festival

Thank you to all of the families who attended the 2017 White Post Farms Fall Festival. We had an amazing time with you and we are looking forward to doing it again next year!

November 10-12th - Steven L. Margolies, MD Family Education Conference

The conference was made possible by the sponsorship and exhibits from the following:

Hemophilia Services Consortium
* CSL Behring
* Pfizer
* Bayer
* Genentech
* Octapharma
* HFA
* Grifols
* Shire
* Kedrion
* Aptevo
* Novo Nordisk

As The End Of The Year Approaches . . .
Please consider supporting the Hemophilia Association of New York. All donations are tax deductible and will allow HANY to continue its mission of support and advocacy for those with Bleeding Disorders.

HANY UPCOMING EVENTS

**January 27** - Blood Brotherhood
“Bowling Night”

**February 24** - Resume Workshop
“Rock Your Resume” Gearing up for Spring/Summer employment (Ages 16-22)

**March/April (TBD)** - Alternative Therapies Sessions

**May 20** - Races at Belmont Park

**June 1** - “A Night at the Museum” Be among the lucky few to spend A Night at the Museum of Natural History (Ages 6-13)

**June 18** - Mathew Lee Greer Golf Classic

**July 29** - Yankees Game

**December (7-9)** - Steven Margolies Family Retreat

Hemophilia Treatment Centers

New York Presbyterian
http://www.cornellpediatrics.com

Mt. Sinai Medical Center
www.mountsinai.org

Northwell Health (formerly LIJ)
http://www.northwell.edu

Albany Medical Center
www.amc.edu

New Comprehensive HTC
Montefiore Hospital
www.montefiore.org
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.

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www.hemophiliafed.org

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

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

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Medical Cannabis
-The Safer Solution to Chronic Pain-
By: Dr. Dustin Sulak D.O.

Chronic pain and opiate addiction have ruined countless lives and changed the landscape of medicine.

Some patients feel let down by the medical system when they are denied effective treatment for chronic pain. Others feel injured by medical providers who have started them on opiate medications that have led to addiction and ruined their lives. Healthcare providers feel frustrated that they cannot do more to safely help patients with chronic pain, guilty for providing effective short-term treatments with harmful long-term effects, and depleted of compassion for patients who need help.

Luckily, there is another solution that is safe, effective, and sustainable. Plus, patients can grow their own.

The vast majority of medical cannabis patients use this herbal medicine to treat chronic pain.

The providers at my medical practice are amazed by the results of medical cannabis in the treatment of chronic pain. Patient after patient tells a similar story, and it goes something like this: “I cut my opiate usage drastically; I’m sleeping better, feeling happy, and enjoying my life more, all with less side effects.”

We find that whenever we see a patient who has been using opiates to treat chronic pain, after starting medical cannabis the opiate dosage decreases by at least 50% in the first week. It’s often more like a 60-80% reduction. Many patients go on to completely discontinue opiate medications over the next several months. They often reduce or discontinue other pain medications as well, including anti-depressants and anti-seizure drugs.

Scientific research tells the same story. A review article published in Life Sciences (2004) concludes, “The administration of low doses THC in conjunction with low doses of morphine seems to be an alternative regimen that reduces the need to escalate opioid dose while increasing opioid potency.” An animal study found that adding a small amount of THC increased the effectiveness of morphine by four to twelve times.

And while cannabinoids, like THC, can work together with opioids to increase potency in the pain centers of the brain, there isn’t a significant effect on the brainstem, the area responsible for decreased heart rate, slower breathing, and ultimately death in the case of an opiate overdose. This means that using cannabis with opioids is safer than using opioids alone.

Patients are starting to figure this out. A study published in the Harm Reduction Journal (2009) looked at 350 medical cannabis users, and found that 65% of them were using cannabis as a substitute for prescription drugs, 40% were using it as a substitute for alcohol, and 26% were using it as a substitute for illicit drugs. Three of the
subjects used cannabis to help them quit smoking tobacco. The most common reasons for the substitution were less adverse side effects, better symptom management, and less withdrawal.

So while we all were told that cannabis is dangerous because it is a “gateway drug,” scientists are now calling it an, “exit drug” within the framework of harm reduction. The goal is to substitute a safer drug for one that’s more dangerous in patients who are unable to achieve total abstinence.

And cannabis is certainly safer than most of our current options for treating chronic pain. In 1999, the Institute of Medicine published a report that stated, “Except for the harms associated with smoking, the adverse effects of cannabis use are within the range tolerated for other medications,” and “there is no conclusive evidence that marijuana causes cancer in humans.”

Unlike opiate medications, cannabis can remain effective at a low dose for years or decades. While opiates can numb the pain and disconnect the mind from the body, increasing risk for inappropriate activity and re-injury, cannabis often does the opposite. Patients report that after using cannabis, the pain is still there but is less intense, less bothersome, and they no longer have to dwell on it. They often feel more connected to their bodies because they no longer have to retreat from the pain. Patients feel able to reclaim their lives from the constant focus on pain.

This does not mean that cannabis is a great medicine for everyone. It has been shown to cause addiction and withdrawal symptoms, such as craving for cannabis, decreased appetite, sleep difficulty, weight loss, and irritability. A study published in the Archives of General Psychiatry found cannabis withdrawal symptoms to be, “similar in type and magnitude to those observed in studies of nicotine withdrawal.”

Cannabis does not have to be smoked, as many patients are using tinctures (liquid extracts) and vaporizers (smoke-free inhalation). Certified patients are able to grow their own or purchase the medicine from caregivers or dispensaries.

Pain is a necessary part of life, helping us to know when to avoid danger, change, rest, or ask for help. Unfortunately, sometimes the pain continues after the threat is gone. Patients in chronic pain are often stressed-out, sleep-deprived, and hopeless. These people need our compassion, understanding, and a safe treatment.

References: