4th Annual Steven L. Margolies MD
Family Educational Conference

Thank you to all the families and speakers who helped make our conference a great success!

This year 25% of attendees were new attendees. The Hemophilia Association of New York was very happy to host the Steven L. Margolies MD. Family Educational Conference. Thank you to Mike Tuberdyke our “Roving Photographer”.

The conference was made possible by Sponsorship and Exhibits from
A special highlight from this year’s conference was “HANY’S Got Talent”. The opening act was George Agnew on guitar, Tyshawn Constantine on bass, and vocals by Linda Mugford. This talent show gave attendees a glimpse of how much talent this community has.

Hemophilia B Doesn't Have Me

By: Jerry McMillan

I was a baby born in the South
My start was humble no silver spoon in my mouth.
Got a bump on my head as most babies do,
It would not go away and my Mama had no clue.

The doctors told the young mother it was hemophilia B,
So no more living in this small southern city.
Moved to New York and nothing was the same,
Gathered around family and stronger the young mother became.

Her little boys became stronger leaders of men,
Challenges came but they beat them back again and again.
Sometimes the oldest son would get knocked down hard,
Never broken or beaten but sometimes scarred.

He up got from the fight just as proud as can be saying,
"Yeah I've got Hemophilia B but it sure as Hell ain't got me!"

Jerry McMillan performing his poem for the very first time at Mohonk
Researchers Explore a Drug-Free Idea to Relieve Chronic Pain: Green Light

By: Will Stone of National Public, Inc.

Ann Jones tried everything short of surgery for her chronic migraines, which have plagued her since she was a child. "They've actually gotten worse in my old age," says Jones, who is 70 years old and lives in Tucson, Ariz. Jones would have as many as two dozen migraines a month. Over the years, some treatments might work initially, but the effects would prove temporary. Other medications had such severe side effects she couldn't stay on them. "It was pretty life-changing and debilitating," Jones says. "I could either plow through them and sometimes I simply couldn't."

In 2018, her doctor mentioned a study that was taking place nearby at the University of Arizona: Researchers were testing if daily exposure to green light could relieve migraines and other kinds of chronic pain. Jones was skeptical. "This is going to be one more thing that doesn't work," she thought to herself. But she brushed aside the hesitation and enrolled in the study anyway. It began with her spending two hours each day in a dark room with only a white light, which served as the control. In the second half of the study, she swapped out the conventional light for a string of green LED lights.

For more than a month, Jones didn't notice any change in her symptoms. But close to the six-week mark, there was a big shift. She began going days in a row without migraines. Even when the headaches did come, they weren't as intense as they had been before the green light therapy. "I got to the point where I was having about four migraines a month, if that many, and I felt like I had just been cut free," Jones says.

Some patients in the study of about 25 people noticed a change in just a few days. For others, it took several weeks. Dr. Mohab Ibrahim, the migraine study's principal investigator and an associate professor at the University of Arizona, says that on average, people experienced a 60% decrease in the intensity of their migraines and a drop from 20 migraines a month to about six. The results of the migraine study aren't published yet. But they build on a small but growing body of research suggesting a link between green light and pain, including animal research done by Ibrahim's team. While there are not yet robust data on humans, some researchers see promise for a drug-free approach that could help with migraines and possibly other forms of chronic pain.

A hunch and a headache

At his office in Tucson, Ibrahim demonstrates a device he has been using with patients. It's a thin vertical stand mounted with green LED lights — an update from his earlier model, which was a simple string of lights. Ibrahim, who directs the chronic pain clinic at Banner - University Medical Center Tucson, became interested in the idea of green light therapy because of something his brother told him about his headaches. Instead of taking medicine, he would sit in a garden and eventually they would subside.

That got Ibrahim thinking about the color green and how green light could be applied as a therapy. "There was a healthy dose of skepticism," he says. "It was kind of strange. Why are you using light to treat pain?" This low-tech approach to treating pain may seem out of sync with Ibrahim's credentials. He's an anesthesiologist with a Ph.D. in pharmacology and toxicology. As he puts it: "Drugs are my tools." But he started to explore the idea anyway, designing an animal study, published in the journal Pain in 2017, that demonstrated that the pain response of rats decreased when they were exposed to green light. "We were able to reproduce it over and over and over again to the point where you just had to follow the story," he says.

Why green?

The idea that there's a link between green light and pain is being explored by several research groups. Research led by Rodrigo Noseda at Harvard
Medical School looked at light sensitivity, known as photophobia, a common symptom of migraines. The research, published in 2016, found that green light is significantly less likely to exacerbate a migraine compared with other colors and, in some cases, can actually decrease the intensity of the headache. The group at Harvard has also shown that green light can "trigger positive emotions" during migraines, in contrast to colors like red, which are associated with negative feelings.

Ibrahim and his research colleagues also found a connection with the visual system. As part of their 2017 study, they fitted tiny contact lenses on the rats. They found that only the animals that could see green, either from an external light or through green lenses, had a drop in their pain response. "We basically made the conclusion that whatever effect is happening is taking place through the visual system," he says. "That's why when we recruited patients; we told them you cannot fall asleep when you're undergoing this therapy."

Ibrahim says there's a lot more to investigate about the biological underpinnings of the green light treatment, but research by him and his colleagues is offering some clues. For example, Ibrahim's 2017 study tested the effect of the opioid reversal drug naloxone on rats that had been exposed to green light. After administering the drug, there was a "complete reversal" of the pain-relieving effects of the green LED. "Whatever the mechanism is, we thought maybe the endogenous opioid system might be involved," Ibrahim says.

Ibrahim says his most recent research supports the theory that green light therapy is working in multiple ways: "It's a concert of mechanisms working in harmony toward a common goal." Ibrahim was awarded funding by the National Institutes of Health to look deeper. Ibrahim is also studying the effect of green light for conditions such as fibromyalgia, nerve pain related to HIV and chemotherapy and a painful bladder condition called interstitial cystitis. The interaction between light and pain

The link between light and pain is a promising area of research, says Mary Heinricher, professor and vice chair for research in the Department of Neurological Surgery at Oregon Health & Science University, but she says she's not yet convinced that color is the most important variable in modulating pain. "The effects of the green light is pretty subtle," Heinricher says. "We need the parallel work showing what are the relevant neural circuits if we are going to make anything tremendously useful for people." She says it also remains to be seen if the green light research translates into humans, who process color differently from how rodents do.

Heinricher doesn't expect that green light will be a primary treatment for chronic pain anytime soon, but she says the research is a laudable and necessary step as we tease out the underlying science. "We have tended to run to drugs and not thought about intervening in the physical environment," she says. "This is a wake-up call. There's something going on there." At OHSU, her team is looking at photosensitivity in veterans with chronic pain, some of whom have a traumatic brain injury, and using functional MRI to see how they process light compared with those without chronic pain. She says it's possible that photosensitivity could be a predictor of chronic pain. Heinricher says her team happened upon this area of research accidentally when they noticed certain cells that facilitate pain responded to a flashlight in a dark lab. "I was quite surprised," she says. "If you had asked me this five years ago, I would have said no way."

"A happy thought"

If green light proves effective in human studies, neurologist Dr. Morris Levin says, he would welcome the treatment. "It is a happy thought. I hope it works," says Levin, director of the Headache Center at the University of California, San Francisco. "A lot of these other treatments don't work as well as we'd like, and a lot of them cause side effects." Migraine sufferers are "very sensitive to environmental stimuli," and Levin says the idea of manipulating light to lessen headache severity is a "plausible" approach. "The problem arises when you try to find exactly what in the environment really stimulates the migraine.
and what in the environment might be changed without too much trouble that would still be really beneficial," he says. Levin says there isn't enough evidence yet to support green light as a truly beneficial treatment for headache pain. "It is very intriguing, but it still has a long way to go," says Dr. Andrew Hershey, who is co-director of the Headache Center at Cincinnati Children's Hospital Medical Center. "Trying to do a classic placebo-controlled study to see if one light works or not is likely not doable in this area," he says, since the patient knows the color of the light. He says positive results from patients who spend time with just a green light may also relate to them spending less time with irritating light, like the blue glow of computers and phones.

**From light box to glasses**

Ibrahim's patient Ann Jones decided to keep the green light, even though the study is over. She discovered that when she stopped doing the treatment regularly, her migraines reemerged. "I made a commitment to go back on the green lights daily," she says. "The very next day I did not have a migraine, and for five straight days I didn't have a migraine." Jones says the only downside is finding time to spend in a dark room with just a green light for company.

In a separate clinical trial, researchers at Duke University are trying to see if that problem can be solved through a wearable treatment. "Having a patient sit in a room with green ambient light is not necessarily conducive to normal life," says Padma Gulur, a professor of anesthesiology, who is leading the Duke study. Gulur's NIH-funded study is looking at how different shades of glasses — clear, blue and green affect postoperative pain and fibromyalgia. She says the early results are encouraging her to pursue larger human studies for multiple conditions. "It just goes to show the power of our nervous system in how it responds and adapts to different stimuli," says Gulur. She says "minimal harm, ease of access and compliance" are all strong cases for seriously considering the feasibility of green light. "Even if we see 50% of patients benefit from this, then already it becomes something worth trying," she says. Some people aren't waiting for more research.

Duane Lowe is a chiropractor with the Department of Veterans Affairs in Grand Junction, Colorado. He works with patients in chronic pain. After reading some of Ibrahim's research, Lowe wanted to see if it could help his own patients. He ordered some green glasses online. "I just gave them to patients to try for a week," he says. "After a very short period of time, patients were coming back giving very positive reviews." So he kept doing it. He makes sure to tell the patients that this is experimental — no one knows how well glasses work compared with the LED light or how long you need to wear them. "I didn't actually have to worry about whether these studies have been done, because the side effects of giving someone green glasses is almost nil," he says. Dr. Mohab Ibrahim enjoys the simplicity of the treatment too. "In my opinion, the most ideal drug or therapy is something that's first safe, effective and affordable," he says.
How Hemophilia Affects Mature Adults

Mature adults may look back and recognize how living with hemophilia has influenced who they are today. Persevering through the challenges of being a child diagnosed with hemophilia when less was known about the condition, and navigating the issues of being a young adult with a bleeding condition can shape one’s perspective. Knowledge and wisdom are some of the benefits that accrue with age, but along with these can also come additional health concerns such as high blood pressure, diabetes, and arthritis; depression and stress; and financial planning and retirement concerns. For those who have lived with hemophilia for many decades, the task of managing these concerns of older age may seem to be less important. However, there are some key points to keep in mind when addressing the effect hemophilia can have on mental health.

Education and support for people living with bleeding disorders and their families is one component of managing psychological wellness. Having control over life decisions and self-advocacy can also be important. For some living with hemophilia, past experiences may serve as a motivator to continue to work toward personal objectives. Others may find the journey more difficult to navigate. Self-help seminars and support groups are some of the resources that may help adults set and attain realistic goals.

"[A reminder to] older adults that there is always somewhere to turn, even in times of immense hardship. All you need to do is ask, and you should never feel ashamed for doing so."

— Judy Bagato
RN, BSN, Hemophilia Specialist

The Risk of Clinical Depression

Mature adults living with hemophilia typically have experienced substantial challenges related to their disease throughout their lives. In some instances, hardships may contribute to the development of clinical depression, which is more common among people living with hemophilia than the general population. The results from one study conducted at a hemophilia treatment center showed that 37% of a sample of patients met the criteria for depression. Of that 37%, 20% had moderate to severe symptoms, and 66% reported having functional impairment due to their depressive symptoms. The authors of the study concluded that the comprehensive care of adults with hemophilia should include depression screening for the potential to improve overall health outcomes.

Finding Support for Complex Issues

For people who acquired human immunodeficiency virus (HIV) and/or hepatitis C (HCV) from virally contaminated blood products, there may be feelings of anger and resentment. The adversity caused by a lack of family or social support during younger years or changes later in life, such as changes in one’s capacity for employment or altered family dynamics, may also contribute to these feelings. Learning effective ways to cope with the stresses of living with hemophilia in older age may help an individual to be resilient to these challenges. If you are experiencing stress that is affecting your day-to-day outlook, it is important to seek help. Reach out to your treatment team to discuss your situation and learn about what help and support may be available.

PAST EVENTS

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

The Hemophilia Association of New York hosted our very first Women’s Symposium on October 18 – 19, 2019. The event addressed the social inequities and health disparities that are found amongst women with bleeding disorders. A special thanks to Estée Lauder for providing makeovers.

ACADEMIC SCHOLARSHIP 2020

In order to qualify applicants must have, or be the child of a person who has a genetic bleeding disorder, and a registered client with HANY.

Applications for the academic year beginning fall 2020 are now available. To request an application please contact 212-682-5510, or email tconstantine@hemophiliaNY.com

PATIENT ASSISTANCE PROGRAMS

Patient Assistance is offered by most manufactures of bleeding disorders treatment medication. If you or someone you care for is being treated for Hemophilia or VWD these programs may help with co-pays, deductibles and gaps in insurance. If you would like information about these programs, please contact your hemophilia treatment center or HANY at 212-682-5510.

MAKE IT YOUR DUTY TO REGISTER EVERY YEAR FOR PATIENT ASSISTANCE PROGRAM RELATED TO YOUR TREATMENT

UPCOMING EVENTS

HFA to Honor Bleeding Disorders History at 2020 Symposium

The 2020 Hemophilia Federation of America symposium will be April 23-26 in Baltimore, Maryland. If you are a registered client of HANY and plan on attending contact us ASAP as we have travel grants available. HFA also provides hotel scholarships for those who are attending symposium for the first time. In order to be considered you must register for the event on HFA’s website by April 9, 2020.

Contact us at 212.682.5510 or visit hemophiliafed.org

HANY UPCOMING EVENTS

February TBD – “Outside the Clinical Box”

March 15 & 16 – Albany Days & READY (March 14 New attendees only)

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

May 17 – Day at the Races at Belmont Racetrack with Art Therapy Session
Children ages 5 – 12 with a bleeding disorder with 1 accompanying parent complimentary admission.

July 22 – Greer Golf Classic

July 26 – HANY 68th Anniversary Gala at Yankee Stadium - Yankees vs. Red Sox

Winter – 5TH Annual Steven L. Margolies MD, Family Educational Conference

Plus, more! Keep an eye open for notices about more events
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.

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.coalitionforhemophilia.org

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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