3rd Annual Steven L. Margolies, MD Educational Conference
December 7-9, 2018

Thank you to all of the families and speakers who helped make our 3rd Annual Steven L. Margolies, MD Educational Conference a great success!

Thank you to Mike Tuberdyck our “Roving Photographer”
Contact our office at admin@hemophiliany.com for the code to view more photos
The conference was made possible by the Sponsorship and Exhibits from the Hemophilia Services Consortium, Hemophilia Federation of America, CSL, Behring, Pfizer, Bayer, Bioverativ, Genentech, Octapharma, Grifols, Shire, Novartis, Spark

What a whirlwind event we just came from. Sometimes when you plan an event such as the Steven L. Margolies Educational Conference in the back of your mind is the worry that some of the speakers may not hit the mark or the attendees won't attend. Or worse you'll have empty rooms the first night and have to 'eat them'.

My expectations of a great conference were met. Mohonk Mountain House is an awesome venue and the staff literally took care of our every need. I've always felt "If you feed them they will come", and come they did but for so much more than the great food.

I think HANY was able to feed the inquisitive mind with: "The New Science of Bleeding Disorders-New Advances for a Life-Long Disease" (Henry Mead); "Understanding Gene Therapy Research and Its Potential Application to Hemophilia" (Laureen Temple); "The Royal Disease: A Family History Update on Queen Victoria" (Louis P. LeGuyader).

We hopefully unraveled some of the insurance issues all face sooner or later with: "Insurance Tends & Issues" (Donnie Akers & Ruthlyn Noel) and Supplemental Security Income & Social Security Disability Insurance (What the Hell are They, How are they Different, and How Do I Qualify?) (Donnie Akers).

There were also sessions on other issues: "Therapy Options- The Emotional Connection" (Cathy M. Tiggs); "Dental Care" (Sue Kovats-Bell); "Overcoming Challenges" (Annie Sukhnanadan); "Aging with a Chronic Condition" (Aliana Soto); and "We Need to Talk" (Christie VanHorne).

We fed physical needs with Mike Zolotnitsky's Aquatic Therapy Sessions. These sessions are so motivating people showed up at the pool at 7:30 AM!

Pat Torrey of GutMonkey, helped to feed the need for the teens to be in their own program and learn to tell their own story. Our two art therapy sessions fed the creative hunger so many children and adults have. We were also so grateful for the "Stop the Bleeding Educational Workshop" (Believe Digital). One of the many highlights was the New York Premier of "Bombardier Blood" with special guests, Chris and Jessica Bombardier. There is nothing that compares to watching this community watching this documentary. You could touch the emotion.

We are already planning the Steven Margolies L. Margolies, MD Educational Conference for 2019.

The Steven L. Margolies, MD Educational Conference

*Article written by Rita Epstein (a parent of an adult son with Hemophilia A, a*
I did not personally know Steven L. Margolies or his family, and yet I feel connected by virtue of the Bleeding Disorders Community. I recently commented on a Facebook posting about Chris Bombardier – and I am sure I echo many of us who feel we are all related and the common threads we share are powerful and vital. We are a unique extended family. Dr. Margolies is described as a man of insight, caring and compassion. After attending last year’s Steven L. Margolies MD, Educational Conference sponsored by HANY and after my husband attended the program this past weekend – I want to assure his family and friends that his legacy continues – his positive influence – his strength – continue to validate and support our community.

The program focuses on families with young children, with teens and yet also makes room for couples who have adult children with a bleeding disorder and even for couples where one partner is affected. We bring a great deal of experience, insight, confusion, need, support and love to the weekend.

Our son is thirty-two years old with a severe-moderate Factor VIII deficiency – we’re the old part of the new generation. We did not live through cryo or infected products. We did not have internet connections when we began. We entered this new world when Monoclate was in trial. In the early 1990s we attended a National Conference where the banner read – A Cure by 2000. Wishful thinking? Hopeful? It’s been a long journey. The history of hemophilia is never out of our thoughts and hearts. What is history to many of us – is a reality in other parts of our world. The need for education, products, physical health, emotional supports, insurance, research, and friendships is ever-present. We need to believe and feel that we are not powerless and that we have a voice. We’ve attended many national and state programs, conferences and meetings throughout the years.

The HANY sponsored family educational conference weekend filled with workshops and training and emotional support continues to fill that missing piece in so many of our hearts. The conference offers many options for speakers and the sense that I wish I could be in two places at the same time. The teen/children’s program is pivotal. It addresses the reality of young people with bleeding disorders as well as their siblings who are as directly affected by the diagnosis. We are not born knowing how to reach out, how to interact, how to feel the feelings, how to communicate and support. Aquatics, Art, Music, Drama, Hiking and lots of laughter and often hard talks about depression, friendships, isolation, and pain are part of this weekend. The growth – the sense that “I am not alone” is saving lives and improving the quality of our newest generation. They are our future.

As parents – we have had our own struggles and frustrations. Many of us were blindsided when the diagnosis came in. Others have witnessed relatives deal with a bleeding disorder and have to work very hard to realize historical experiences are not our new reality. We are often haunted by the past. Our presence at these conferences for new parents, teens and our peers can serve as a reassurance that you can come out the other side of the mountain. True you sometimes can’t climb or circumvent – sometimes we have to barrel right on through – but there truly is...
light at the other end. I remember when Chris Bombardier was preparing to climb Everest. He talked about mountains that we all have to climb. That became my visual metaphor for so many moments in my life. Chris’s climb became my journey as well.

There were workshops on the science and advances in the medical field, insurance, social security and current research. New products, new hopes, new dreams. The emotional workshops addressed the reality we all share. A brave face, a positive attitude, an upbeat approach often mask the pain, the sadness, the resentment, the isolation, the fear so many of us experience as part of the bleeding disorders community. The pain is real and it’s not only physical.

I believe that taking control of the facts – learning as much as we can about the technical aspects of a bleeding disorder – connecting with medical, scientific, insurance and pharmaceutical leaders helps us feel that we have some control over a medical situation that often has a life of its own.

We all need help with the emotional aspect. We all need support, compassion, validation and a shared sense that we are not alone.

The conference presenters included attorneys, doctors, social workers, advocates, art therapists, nurses, historians, actors, hikers, professors, physical therapists, parents and people with bleeding disorders. Gratefully – there are many repeat presenters from previous years. The energy and excitement during this weekend is palpable. A separate thank-you and warm hug to Patrick Lynch and Chris Bombardier and their team for helping us move to a new level of involvement and empowerment. The sharing of their film, “Bombardier Blood” is a visual and visceral reminder of the strength we all possess. We all have a story – we all have a history and our bleeding disorder connection binds us together on this journey.

Thank-you to Linda Mugford and the HANY team. Thank-you to the Steven L. Margolies Family. There is strength in numbers – there is power in knowledge – there is hope in friendships. Sometimes we don’t hear about how something we said or heard made a difference in someone else’s life. Stop the Bleeding programs have a ripple effect. HANY has once again changed lives and the ripples continue.

**Excess Weight, Obesity Affecting More Hemophilia Patients, Study Shows**

*By: Marta Figueiredo*

About a third of European and North American hemophilia patients are overweight or obese, which is associated with increased joint dysfunction and chronic pain, according to a recent review study.

The review, “Obesity in the global hemophilia population: prevalence, implications and expert opinions for weight management,” was published in the journal *Obesity Reviews*.

According to the World Health Organization, obesity has tripled in the last 30 years, affecting about 13 percent of adults worldwide. Also, 39 percent of adults are considered overweight.

Excess weight and obesity may be harmful to hemophilia patients, as there is added pressure on the joints, making bleeds more
likely. Repeated joint bleeding can lead to hemophilic arthropathy, a debilitating condition characterized by joint impairment, chronic pain, and diminished quality of life.

While increasing evidence has highlighted the negative impact of excess weight and obesity among people with hemophilia, its frequency in this patient population remains unclear.

Researchers evaluated the frequency and clinical impact of obesity/overweight in the global hemophilia patient population.

The review of published studies within the last 15 years identified 90 relevant studies, of which 28 had data on the number of hemophilia patients who were overweight or obese, or the percentage among that population.

Analysis on those 28 studies showed that 17% of hemophilia patients are estimated to be overweight/obese, and that this number increased to 31% when the European and North American populations were analyzed separately.

The results also revealed that overweight/obesity is more frequent in adults (43.3%) than in pediatric (26.9%) hemophilia patients. The prevalence of these conditions is higher in European (49.1%) rather than in North American (38.5%) adults, but inverted trends were found for children (18.8% in Europe vs 30.6% in North America).

Also, over a period of 10 years, overweight/obesity showed a 20% increase in adults and a 40% increase in children with hemophilia.

This data points to a significant occurrence of overweight/obesity in European and North American patients with hemophilia, particularly in the adult population, and a rapid increase in its frequency in pediatric patients over a relatively short period.

While these frequencies seem to be similar to the ones reported for the non-hemophilia population, the fact that data outside Europe and North America is limited and that most hemophilia studies do not report this type of information may mean that the worldwide frequency of clinically significant excess weight in hemophilia patients is underestimated.

Additional studies are needed to assess the global frequency of overweight/obesity in hemophilia patients. “Although hemophilia itself is unlikely to be a causal factor for obesity, the disease may indirectly lead to weight gain or difficulty in weight loss if patients reduce levels of exercise due to muscle/joint pain, restricted range of movement or fear of bleeding,” the researchers said.

The team also found that overweight/obesity in these patients may reduce venous access for infusion of coagulation factor, increase the risk of impaired muscle strength and function, joint surgery, and cardiovascular problems, and negatively affect their psychological well-being (with studies reporting more than 30% of patients showing depression).

The researchers noted that while additional studies are needed to better understand the clinical impact of overweight/obesity in these patients, these conclusions already highlight the importance of weight management.

They proposed a series of additional methods to assess overweight/obesity in hemophilia patients, as well as recommendations to prevent or manage overweight/obesity in adult and pediatric patients.
The prevention and management of overweight/obesity in the context of [hemophilia] has additional considerations with regard to patient education, psychological support and, perhaps most importantly, engagement in physical exercise,” they concluded.

HANY SCHOLARSHIP

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. Applicants must also reside within the 14 southeastern counties of New York State.

*Applications for the year 2019 will be available soon. For more information contact 212-682-5510, or email tconstantine@hemophiliaNY.com*

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 MANDITORY TO REGISTER EVERY YEAR FOR YOUR SPECIFIC ASSISTANCE PROGRAM*

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.

Our Best Wishes for a Happy and Healthy New Year!

UPCOMING EVENTS

HFA to Honor Bleeding Disorders History at 2019 Symposium

The 2019 Hemophilia Federation of America symposium will be April 4-7 in San Diego, California. If you are planning on attending contact the office ASAP, we have some travel assistance funds available. Those who are registered with HFA are also eligible for first time attendee scholarships.

HANY UPCOMING EVENTS

January 19 - Outside the Clinical Box
Session 1: Reiki with Michael Emma, OTR/L

February 3 – La Fuerza de la Esperanza (Driven by Hope) with Joana Baquero (Spanish Translation) Book Launch

March 2 - Outside the Clinical Box
Session 2: Acupuncture

March 29 - 31 - S.A.I.L
(Self Advocacy, Independence & Leadership)
Training at Camp Quinipet at Shelter Island, NY with Guttnmonkey (Ages 13-18)

May 19 - Day at the Races - Belmont Race Track

June 7 - Night at the Museum
Be among the lucky few to spend a night at the Museum of Natural History (Ages 6-13)

June 17 - Greer Golf Classic

July 21 - HANY 67th Anniversary Gala at Yankee Stadium - Yankees VS. Colorado Rockies
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.

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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

Montefiore Hospital
www.montefiore.org