**HANY SCHOLARSHIP**

**2019 SCHOLARSHIP APPLICATIONS ARE NOW AVAILABLE!**

In order to qualify for the 2019 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.

For applications contact 212-682-5510 or email tconstantine@hemophiliany.com.

**DEADLINE MAY 10, 2019**

**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**

**ONLINE HEALTH INFORMATION: IS IT RELIABLE?**

*By: Paul Clement*

It’s an exciting time for people with inhibitors. In addition to bypassing agents, new products may prevent or control bleeds more effectively than previous products, while reducing the burden of treatment. But where can you find accurate information about these products?

Most commonly, people turn to the internet for health information. The problem? Much of this information is false or biased. And surveys have found that most internet users can’t detect bias and don’t know how to critically evaluate the health info they find online. How do you know what’s reliable? Here are some questions to ask before trusting what you read on a website.

**Who sponsors or funds the website?** Knowing who funds the website may indicate if the website has a bias. For example, while a pharmaceutical company will provide product information on its website, it also wants to influence you to buy its products—such as inhibitor therapies. Although the info on pharmaceutical websites is usually correct because the companies must follow FDA regulations, it can also be biased. Sites may contain “errors of omission”— when data is left out that might reflect badly on the product. Pharmaceutical websites may not provide all the facts you need to make an informed decision.

A website address, or URL, can help identify the funding or hosting. For example, in the URL www.kelleycom.com, the website name, or *domain*, is kelleycom. That’s followed by the *domain extension* .com. The domain extension tells you what kind of organization is funding the website. Here are some domain extensions:

- **.GOV** identifies a US government agency, such as the Centers for Disease Control and Prevention (cdc.gov) or National Institutes of Health (nih.gov).
.EDU identifies an educational institution, like a school, college, or university; this can include your hemophilia treatment center (HTC) if it’s also a teaching hospital.

.ORG usually identifies nonprofits: professional groups, and scientific, medical, or research societies; and advocacy groups like National Hemophilia Foundation (hemophilia.org) or Hemophilia Federation of America (hemophiliafed.org). Many HTCs use .org.

.COM is the most common domain extension, identifying commercial websites such as businesses, pharmaceutical companies, and sometimes hospitals.

.HEALTH identifies healthcare professionals, pharmaceutical companies, medical associations, hospitals and health systems, health products and services, public health organizations, and health blogs and publications. Organizations wishing to operate a .health website can use this extension only after being validated as a qualified member of the health industry.

Different domain extensions are associated with various levels of trustworthiness. Generally, .gov sites and .edu sites have the highest trustworthiness (about 70%), followed by .org and .com.¹²

A company can set up almost any website name—it doesn’t have to be the company name—or may use another company to host its site, making it harder to learn who actually funds or sponsors a website. Websites that display a company’s name and products are branded websites. Their intent and biases are easy to determine. Websites that don’t mention any company name or product are unbranded. On unbranded websites, it’s harder for visitors to determine whether the site has a bias.³

Why would a company run a website without its name? For pharmaceutical companies, direct-to-consumer marketing of drugs is heavily regulated and subject to an FDA policy called “fair balance.” Fair balance requires pharma advertisers to present the drug’s negatives alongside the positives, including side effects and other conditions that make taking that drug risky. An unbranded website is not subject to the fair balance rule and is lightly regulated, allowing the company to quickly get a website running, increase “disease awareness,” and offer consumers more educational info about a medication—but not mention side effects. And this may mean a greater risk of misleading consumers. Make no mistake: pharma is funding these websites to gather general patient information or to make money by converting patients to their product. Also be wary of unbranded sites that require a “registration” process to access—websites should not ask for personal info.

For example, one pharmaceutical company runs a lightly branded inhibitor website that heavily pushes the results of the SIPPET study, suggesting that patients use a factor VIII product with von Willebrand factor (VWF). No product names are mentioned on the site, and the company name is only in small text at the bottom of a page. But it turns out that this company is also the only company selling a plasma-derived factor VIII-VWF product in the US—and this product is being promoted by the website. So, although the website provides good info on inhibitors, it also tries to convince consumers to switch to a VIII-VWF product (the company’s own), while at the same time avoiding FDA fair balance rules.

Who reviewed the info before the website’s owner posted it?

Health-related websites should provide the credentials of people who prepared or reviewed the material. Here are some questions to ask yourself: Do you recognize the author? What knowledge or skills does the author have in the subject? What else has the author written? Does the author
acknowledge other viewpoints and theories? Does the site have an editorial board? Is the info reviewed by editors or experts before being posted? Does the author clearly state what’s fact or opinion? Are opinions or advice set apart from info that is “evidence based” (based on research results)? Testimonials from people who have tried a particular product or service are not evidence based and usually can’t be confirmed.

**How does the website document its supporting evidence?**
Websites should identify the medical and scientific evidence that supports the material presented. Medical facts and figures should cite references, such as articles published in medical journals. Be skeptical. You want current, unbiased information based on research. An article that cites no evidence and includes no references is a red flag. Things that sound too good to be true often are. Always cross-check multiple sources of info from different websites. Never rely solely on one website.

**How current is the info on the website?**
Medical research and knowledge are constantly progressing, sometimes making old material obsolete. How do you know if the material you’re reading on a website is up-to-date? Articles and web pages should be dated. Experts should review and update articles regularly, and then label the material with the most recent review date. Even if the info has not changed in a long time, the site owner should indicate that it’s periodically reviewed to ensure it’s still valid.

**Can you communicate with the website’s owner?**
Can you easily find contact info on the web page? Does the website provide names, emails, and a physical address? Or is the only way to contact the owner through a webform? More red flags: anonymous articles, and lack of contact info. Websites should always offer a way for users to contact the owner with problems, feedback, and questions.

**What about social media?**
According to a PwC Health Research Institute survey, more than one-third of US consumers use YouTube, Facebook, or Twitter to find medical information. And 90% of respondents aged 18 to 24 said they would trust medical info shared on their social media networks. Also, 80% said they would share their own personal medical info online (more than twice the percentage of 45- to 65-year-old participants).

Social media is great for support, but as a source of reliable health information, it’s inadequate. Take anything you learn on a social media site with a grain of salt, and verify by visiting more reliable websites.

**Be a savvy health info consumer!**
Just knowing that some websites are biased and others are not can help you search for health information. Start with searches on .gov and .edu sites. When searching on .com sites, ask yourself why the sponsor is providing the website.

Learn how to use the US National Library of Medicine, National Institutes of Health database PubMed (ncbi.nlm.nih.gov/pubmed). PubMed contains more than 28 million citations for peer-reviewed biomedical literature from Medline, life science journals, and online books. Many of these citations are abstracts (short descriptions of an article); others are full text. Most PubMed citations are from medical journals, and the jargon makes difficult reading at first. But the reading gets easier over time because you’ll see the same terms over and over, and eventually, some will stick with you. Several websites, including Medical Library Association’s What Did My Doctor Say? Page (mlanet.org/p/cm/lh/fid=580), can help you decipher “medspeak.”

In addition, several organizations rate the reliability and credibility of health-related websites for consumers. The best known is Health on the Net Foundation (HON). HON issues certificates to medical and health websites that agree to abide by the HON Code of Conduct. The HONcode symbol
indicates that a site follows HON standards, so readers know the source and purpose of the medical info. But remember: HON does not verify the truth of the info on websites. More than 8,000 websites display the HONcode. The HON site has a search engine, a toolbar, and search apps.\(^5\)

The bottom line: Not everything you read on the internet is true! Visit respected sites, and always verify information on multiple sites. Use dedicated health search engines like HON’s. Be skeptical of what you read online. Be aware of bias. And if you need clarification on a topic dealing with bleeding disorders, contact your HTC hematologist.

**Different Treatment Strategies May Affect Sports Participation in Hemophilia Patients, Study Suggests**

*By: Alice Melão*

*Hemophilia News Today*

Hemophilia patients who take intermediate-dose preventive medication may experience more of an age-related decline in sports participation, joint status, and physical functioning than those on a high dose, a population-based study suggests.

The study, “Sports participation and physical activity in adult Dutch and Swedish patients with severe haemophilia: A comparison between intermediate- and high-dose prophylaxis,” was published in *Haemophilia*, the official journal of the World Federation of Hemophilia.

Development of more stable and effective engineered versions of clotting factors has improved the quality of life of people living with bleeding disorders. In particular, the increased availability of recombinant clotting factors and the introduction of preventive, or prophylactic, replacement therapies have allowed hemophilia patients to engage in a more active lifestyle and participate more in sports.

Because sports and physical activity have become more important parameters for outcomes in the hemophilia population, it has also become important to better understand the implications of these activities on treatment regimens and bleeding risk.

The National Hemophilia Foundation has categorized different types of sports based on their potential risk of bleeding. These categories range from safe-risk sports, which include those that have a low impact and with a low collision risk, such as walking and swimming, to moderate or high-risk sports, which include soccer, boxing, and rugby.

In this study, Dutch and Swedish researchers compared age-related differences in sports participation and high-risk sports between adults with hemophilia in the two countries, which each use different treatment strategies.

The study included 103 adult patients, of whom 71 — 43 from the Netherlands and 28 from Sweden — completed the sports questionnaire. The study also included 73 healthy volunteers from both countries.

Both groups of patients included mainly (87%) patients with severe hemophilia A, and the average age was 26 years.

In general, the treatment regimen was significantly less intensive in the Netherlands, with prophylaxis starting later in life — by a median age of 5 years compared with 1.7 years in the Swedish group — and with half of the current weekly prophylactic dosing.

Evaluation of the participants’ clinical outcomes revealed that the prevalence of joint damage in the Dutch group was double that in the Swedish group. Dutch patients also seemed to do slightly fewer activities and have a lower quality of life.

Researchers found that Dutch hemophilia patients had a trend for worse joint damage and more limited physical functioning with age, while Swedish patients remained stable.
All participants who completed a sports questionnaire reported being active in some kind of sport, with 59.2% of the patients engaged in moderate to dangerous (high-risk) physical activities.

The most commonly practiced sports were different between the two countries. Still, cycling, swimming, walking, fitness, bowling, billiards, skiing, jogging, and football (soccer) were among the 10 most common sports reported by both groups.

Researchers saw a clear decrease in how often Dutch patients engaged in sports per week with age, but this was not seen in Swedish patients.

An age-related decline in the proportion of hemophilia patients who engaged in high-risk sports in the Dutch group was also reported. While 75% of Swedish patients ages 30–40 practiced high-risk sports, only 28% of Dutch patients in the same age range reported doing these same activities.

The team did not find any significant correlation between sports participation and clinical outcomes or treatment and bleeding parameters.

These findings show that Dutch hemophilia patients, “who received less intensive treatment” experience “age-related decrease in (high-risk) sports participation and joint health and a decrease in physical functioning,” according to the researchers.

Additional studies are still warranted to further explore the impact of the frequency, duration, and intensity of physical exercise in hemophilia populations. Such studies may provide better insights on the outcomes of these patients and support counseling on sports participation.

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**PAST EVENTS**

**October 20 - Women’s Group**
The women of Blood Sisterhood participated in a women’s health session hosted by Martha Boria of the Hemophilia Federation of America, then enjoyed an amazing paint party at Muse Paint Bar.

**November 3 - Blood Brotherhood**
The men of Blood Brotherhood participated in an employment rights and American Disabilities Act information discussion facilitated by Donnie Akers, then enjoyed an evening of cracking codes at Skyscape NY.

**January 26 - Outside the Clinical Box**
Michael Emma, OTR/L (Reiki Master) facilitated our very first alternative therapy information session, which was a great success!
February 24 - Driven by Hope/ Dental Care
Joanna Baquero author of *La Fuerza de la Esperanza (Driven by Hope)* had an inspirational talk about her struggles living with a rare bleeding disorder, and Karla Zevallo of Takeda facilitated a dental care session to our Latin American community.

February 27 - Adults Over 50 Financial Fitness
Attendees learned about the 5 habits of how to become financially fit and how to budget for the future.

March 29 - Self-Advocacy, Independence, & Leadership Retreat for Teens
Our teens participated in a training preparing them for adulthood & enhancing their skills to live independently at Camp Quinipet, facilitated by GutMonkey.

A SPECIAL THANK YOU TO ALL SAIL SPONSORS TAKEDA, GENENTECH AND CSL

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**Help Support Our Mission of Serving Those With Hemophilia & Bleeding Disorders**

**When:** Sunday May 19, 2019  
**Time:** 12:00 PM  
**Location:** Belmont Racetrack, Queens, NY

**Tickets:** $75  
Children 5 – 12 years old with a bleeding disorder, siblings and 1 accompanying parent FREE

Ticket includes:  
Entry fee  
Brunch Buffet/Soft Drinks  
Program agenda  
Art Therapy workshop (Ages 5 -12) *YOU MUST RSVP*

PURCHASE YOUR TICKETS ON OUR WEBSITE  
WWW.HEMOPHILIANY.COM/EVENTS/FUNDRAISING  
OR MAKE CHECKS PAYABLE TO:  
HEMOPHILIA ASSOCIATION OF NY  
131 WEST 33RD STREET SUITE 11D  
NEW YORK, NY 10001  
CHECKS MUST BE RECEIVED NO LATER THAN MAY 8TH

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**HANY Upcoming Events**

April 27 - Outside the Clinical Box  
Session 2: Acupuncture & Chiropractics

April (TBA) - Blood Brotherhood

April 17 - Men Over 50

May 19 - Day at the Races - Belmont Race Track

May (TBA) - Women's Group

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

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The New York Blood Center has developed a Bleed Disorders Resource Guide provided by the New York Blood Center. This guide serves as a resource for bleeding disorder patients and their families. It is designed to help patients learn more about the insurance coverage options as well as provide information on programs that may offer premium assistance and/or assistance with medication co-pays and deductibles. Included in this guide is a list of resources which has been compiled as reference tool.

If you would like a copy or PDF version contact HANY
Get more out of activity tracking with HemMobile®

HemMobile App + Striiv® Wearable

- **TRACK ACTIVITY**
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  Photograph, map, and log each bleed
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HemMobile was designed to help you keep track of your bleeds, infusions, and factor supply.

It can also help you keep track of your daily activities and, when paired with the Striiv wearable, it can track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level and dosing plan. Download the app, pair your Striiv wearable, and start tracking!

Download the app, pair your device, and start tracking

Visit [www.hemophiliavillage.com](http://www.hemophiliavillage.com) to learn more about HemMobile
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.

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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

New Comprehensive HTC
Montefiore Hospital
www.montefiore.org

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