

CHAPTER

SUMMER 2019

Factors

Are You Ready?

Unite

for Bleeding Disorders

SATURDAY, AUGUST 24, 2019

MHA WALKATHON
FACTS & TIPS
PAGES 8 & 9



**Midwest
Hemophilia
Association**



Join us for a weekend
of fun and education!

**SATURDAY & SUNDAY,
SEPTEMBER 14-15, 2019**

**@ Embassy Suites by Hilton
Kansas City/Olathe**

**10401 S. Ridgeview Road
Olathe, Kansas 66061**

NEW! REGISTER ONLINE!

www.midwesthemophilia.org/events/

Registration deadline is August 24, 2019.

*MHA will cover the cost of a hotel room on Friday night for anyone driving
in 150+ miles. Contact mhaevents@midwesthemophilia.org for details.*

WEEKEND ACTIVITIES

ADULT EDUCATION

YOUTH & TEEN PROGRAMS

CHILD CARE

**MEN'S & WOMEN'S
BREAKOUT SESSIONS**

RAFFLE

RECOGNITION & AWARDS

- Top Walk Fundraisers
- Camp "Big Stick" Celebration
- Academic Scholarship Winners
- Volunteer of the Year
- Top Golf Teams

AND MUCH MORE!



**Midwest
Hemophilia
Association**

Chapter Factors is published by:

**The Midwest
Hemophilia Association**

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Brand names of treatment products are provided for information only. They are not an endorsement of a particular product or company by MHA. Acceptance of advertising for products and services in Chapter Factors in no way constitutes endorsement by the Midwest Hemophilia Association.

FROM THE BOARD PRESIDENT



In this issue of Chapter Factors, you will find a ton of information about our fundraising efforts and upcoming events. I hope you find one or many opportunities to plug in.

Business has continued with the Board of Directors and the hiring committee is nearing the end of their search for a new Executive Director. In an effort to improve communication, we continue to update our community contact database. If you receive a phone call, email, or postcard, please respond so we can ensure your information is updated or added.

The camp committee and helpers are busy planning details for summer camp. The IT/Tech team is adding, deleting, and modify information (given short notice) on the website to keep it up to date. The advocacy committee is learning new information and gearing up for a new PSA project in conjunction with the Gateway Hemophilia Association. Event planning committees are working hard to put together details for our Unite Walk fundraiser, the Annual Golf Tournament, Family Education Weekend, and Wichita Education Day.

Thank you chapter and industry members for your verbal, tangible, and financial support! Without you, we would not exist!

If you have questions, concerns, or ideas to share please feel free to contact me or any of the board members!

We are moving forward with excitement for new things to come!

Sincerely,
Angela Brown
MHA Board President
angela.brown@midwesthemophilia.org



Community Contact Campaign

We are needing to update our community contact information and do it in a way that makes for easy record keeping now and going forward.

Why? We don't want anyone to miss an event invitation, community update, and/or newsletter. The only way to guarantee that you receive this information is to update your contact information. It's a simple task:

- ✓ Go to our website: midwesthemophilia.org
- ✓ Click on "BECOME A MEMBER" tab
- ✓ Fill out the information
- ✓ Hit "JOIN"!

Please note: There is currently no fee required to do this. We wanted to avoid double dipping to those who paid their activity/membership dues at Family Education Weekend last September.





QUICK NOTES

Fun All Around at Trivia Night in KC

A crowd of 50-plus people enjoyed fun, food and competition at the MHA Trivia Night. The event was held Saturday, June 8, 2019 at Parlor KC in Kansas City, Missouri. Attendance included both community and non-community members.

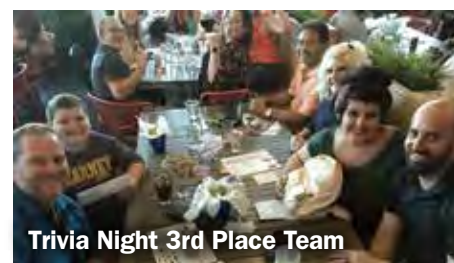
Teams competed for prizes, which included four Kansas City Royals tickets and parking pass donated by Central Plains Cement Company, four Sporting KC tickets donated by Sporting KC, and \$100 donated by Niki Bird. The Platinum Sponsors for the event were CSL Behring and CVS Specialty. Table Sponsors were ARJ Infusion Services and BioEthics Advantage. All proceeds will be used to fund MHA programming.



Trivia Night 1st Place Team
"Low Expectations"



Trivia Night 2nd Place Team
"4?"



Trivia Night 3rd Place Team

Georgia Northway Scholarship Recipients Announced

MHA would like to congratulate the recipients of the 2019-2020 Georgia Northway Scholarship: William Carter, Kolbe Madden, Ramsey Divine, and

Elizabeth Hancock. This year, each student received an award of \$5,000. The scholarship amount is based on a percentage of the fund balance at the time the scholarships are awarded.

The scholarship is offered through MHA and administered by Truman Heartland Community Foundation (THCF). It is available to high school seniors and college students diagnosed with a blood disorder pursuing an undergraduate degree. To qualify for this scholarship, applicants or their family (if under 21) must be members in good standing with MHA. THCF handles over \$250,000 of various scholarships every year and does a great job for MHA.

The scholarship began in 2003 after MHA was notified that Wichita, Kansas resident Georgia Northway had named MHA as a beneficiary of her estate. Ms. Northway's two sons had passed away due to complications from hemophilia and wished to create a scholarship fund for individuals with bleeding disorders. Information relayed to MHA stated that she had thought of MHA because she received the *Chapter Factors* newsletter.

To date, over 30 scholarship grants have been awarded in the MHA community. The scholarship is





renewable, which means students can apply and potentially receive funding as an upper classman and not just during that freshman year. The goal is to continue offering the scholarship so today's recipients will be tomorrow's leaders.

Congratulations to this year's award recipients!

Support Your Walkers!

Show your love and support for a friend or family member with a walk route sign at the Unite For Bleeding Disorders Walk!

The 24" x 18" signs with messages of honor or remembrance may be reserved for \$50 each. Signs will be placed along the route for walkers to view during the walking event. Some examples would be Walk Team Name, We Walk For..., In Memory of..., or Go Spencer Go!.

For more information or to reserve a sign for the event, contact Angela Brown at mhaevents@midwesthemophilia.org. Payment can be mailed to MHA, Walk Pathway Sign, 8900 State Line Rd., Suite 411, Leawood, KS 66206. Money and wording is due by August 9, 2019.

RIGHT: Attendees at the Dodge City Education event competed in Minute To Win Games.

BELOW RIGHT: Nine vendors and industry members provided information at the event held at Guymo Petro Restaurant in Dodge City, KS.

BELOW: Competitors raced to stack Fruit Loops during a game at the Dodge City event.

Minute To Win It Education Event Held in Dodge City, KS

MHA presented the education event Minute To Win It - Bleeding Disorders Awareness Edition on Saturday, June 15, 2019 at Guymo Petro Restaurant in Dodge City, Kansas. Attendees visited with industry representatives and participated in games during the event.

Approximately 30 people gathered at the provided lunch and listened MHA Board Member Bridget Castro as she discussed resources for parents giving their own school inservices, which received positive feedback. Attendees also had the opportunity to participate in a variety of Minute to Win It games. The competitions, including marshmallow toss and Fruit Loop stacking, were a big hit will all. Attendees were given tickets to the Long Branch Lagoon waterpark at the conclusion of the event.

The event featured nine tables from vendors and industry members. Thank you to event sponsors CSL Behring, CVS Specialty and Novo Nordisk.



CALENDAR OF EVENTS

August 24, 2019

UNITE for Bleeding Disorders Walk

Shawnee Mission Park
Shawnee, KS

September 13, 2019

21st Annual MHA Golf Tournament

WinterStone Golf Course
Independence, MO

September 14-15, 2019

27th Annual MHA Family Education Weekend

Embassy Suites
Olathe, KS

October 3-5, 2019

71st Annual NHF Meeting

Anaheim, CA

October 19, 2019

Wichita Education Event

Drury Broadview Hotel
Wichita, KS



ADYNOVATE

[Antihemophilic Factor
(Recombinant), PEGylated]

ADYNOVATE[®] is FDA approved for
children and adults with Hemophilia A

PROVEN PROPHYLAXIS +
SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments **YOUR WAY**

*ADYNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE[®] [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis [40–60 IU/kg] and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.^{1,2}

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis [40–50 IU/kg] vs on-demand [10–60 IU/kg] treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.¹

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds.^{1,2}

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds.¹

Talk to your doctor to see if ADYNOVATE treatment
may be right for you and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

DETAILED IMPORTANT RISK INFORMATION (cont'd)

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238–246. 3. Data on file; Shire US Inc.



ADYNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Issued 05/2018

MHA WALKATHON FACTS & TIPS

SATURDAY, AUGUST 24, 2019

Registration 9:30 am • Event Start 10:00 am

@ Shawnee Mission Park • 7900 Renner Road, Shawnee, KS

It's time for the MHA Walkathon! Formerly the National Hemophilia Walk, Unite For Bleeding Disorders Walk is a nationwide event that raises funds and awareness for all bleeding disorders. Participants raise money, locally and nationally, for crucial research, advocacy and education by joining together in the fun and festive event. Whether you're a seasoned walker or new to the event, MHA will benefit from your participation. It's not too late to start a team or give a strong push for your fundraising efforts.

QUICK FACTS

• HOW DO I REGISTER?

To register, visit www.uniteforbleedingdisorders.org and click "Find a Walk" and search for walks in Kansas. Once on the local page, click **Register Now** to form your team!

• HOW IS THE MONEY USED?

100% of every dollar raised stays here locally and directly supports MHA's advocacy, education and research initiatives.

• WHAT IS THE AVERAGE AMOUNT THAT PARTICIPANTS RAISE?

Participants raise \$120 on average. However, there is minimum fundraising of \$25 to receive a 2019 walk tshirt.

• CAN MY CHILD PARTICIPATE IN THE WALK?

Yes! The walk is a family event for all ages. Strollers are welcome.

• HOW LONG IS THE ROUTE?

The MHA Walk is approximately one mile long.

• WHAT IF IT RAINS?

In most cases, the Unite For Bleeding Disorders Walk will take place rain or shine! If there is dangerous weather, we will notify participants to make alternate plans.

• HOW DO I TURN IN DONATIONS?

Funds raised online are automatically directed to MHA. For funds raised offline, please use the walker collection envelope to turn in money at the walk.

• WHO DO I MAKE CHECKS PAYABLE TO?

Checks should be made payable to Midwest Hemophilia Association (MHA). If the check is on behalf of an individual participating or fundraising for the walk, please indicate his/her name in the memo area.

DOUBLE YOUR DONATION WITH A MATCHING GIFT

Many employers support their employee's charitable engagement with a matching gift program. They might double or even triple your donation to the Unite For Bleeding Disorders Walk. They might also even match your spouse's donation. Just follow these three easy steps:

1. Visit www.uniteforbleedingdisorders.org and click on "Matching Gifts" in the navigation bar. Use the search box to see if your employer matches charitable donations.
2. If your employer is listed, they will want your state tax id number to complete the matching gift form. Contact MHA Treasurer Jaci Colter at treasurer@midwesthemophilia.org for the MHA number.
3. Be sure to remember to enter the amount of the match donation in your pledged donations on your fundraising page, so you get 100% credit for the matching donation!

Fundraising Tools

We know fundraising can be scary, so thank you for stepping up. All funds raised by our Unite For Bleeding Disorders Walk stay here in the Kansas and Western Missouri area to help families send their children to camp, create a pool of emergency funds, offer guidance and support for newly diagnosed families. Visit www.uniteforbleedingdisorders.org and click on "Fundraising" for step-by-step fundraising tutorials, including:

- ✓ How to register and start strong with your first donation
- ✓ How to customize your personal fundraising page
- ✓ How to share on social media
- ✓ Quick tour of your fundraising dashboard
- ✓ Unite Mobile App Tour
- ✓ How to send a fundraising email
- ✓ How to send an email update or customized thank-you email



8 Steps to Raise \$1,000

This may be the first time you've participated in a fundraising event. We'd like to show you just how simple it can be. Just follow these eight easy steps and you'll be well on your way.

Have you set a higher goal for yourself than \$1,000? Great! Simply adjust the minimum donation amount you're asking for each potential donor—and increase the number of people you're going to ask.

- 1 Donate to **yourself**.
It all begins with you! \$75
- 2 Ask **4 family members**
to donate \$50 each. \$200
- 3 Ask **8 friends**
to donate \$25 each. \$200
- 4 Ask **5 coworkers**
to donate \$25 each. \$125
- 5 Ask **your boss** for a
company contribution of \$100. \$100
- 6 Ask **4 neighbors**
to donate \$25 each. \$100
- 7 Ask **4 local business** you frequent
(coffee shop, bakery, etc.)
to donate \$25 each. \$100
- 8 Ask **4 professional people** (your doctor,
dentist, lawyer, insurance)
to donate \$25 each. \$100

TOTAL \$1,000

Unite
for Bleeding Disorders

**For questions, contact Midwest Hemophilia Association at
MHAevents@midwesthemophilia.org**



21st Annual

MHA GOLF TOURNAMENT

September 13, 2019

WinterStone Golf Course

17101 E. Kentucky Road
Independence, MO 64058

Check-In Time 7am

Tee Time 8am

**AWARDS BANQUET
RAFFLE
HOLE CONTESTS**

Breakfast & Lunch Included

Support MHA while having fun by participating in the 21st Annual MHA Golf Tournament on September 13, 2019! Check in time will be at 7:00am with a shot gun start at 8:00am. Lunch will be provided after the rounds with an awards banquet following the conclusion of play.

This year's tournament will be held at a new location, WinterStone Golf Course in Independence, MO. Participants will be pleased with the quality of the golf course, which is well maintained and provides a high level of service from its staff and head golf pro. Its large venue, The Pavilion, will furnish ample space for golfers to relax and mingle during the post-tournament awards banquet. The space is a climate controlled open-air facility that features flat screen TVs for sports viewing and accommodates seating for 150 people.

The WinterStone Golf Course opened in 2003 and is in the second phase of a development project that began with a limestone mine. The wooded setting is spectacular with elevation changes, towering trees, lakes and creeks combining to create an Ozarks-like feel.

For more information about the tournament or to become a sponsor, contact MHA Golf Tournament Fundraiser Chair David Moss at david.moss@grifols.com.

To download the registration form or more information, visit
<https://midwesthemophilia.org/events/mha-golf-tournament-2/>



SPONSORSHIP OPPORTUNITIES:

Title Sponsor - \$10,000

Top Billing of Name & Logo on Event Banner, 3 Teams of 4, Tee & Green Signage, Recognition at MHA Family Education Weekend, in the MHA Newsletter and on MHA Facebook Page

Lunch Sponsor - \$2,500

1 team of 4, Recognition During Lunch with up to 5 minute, Non-Branded Presentation

Golf Cart Sponsor - \$2,000

1 team of 4, Name & Logo on All Team Golf Carts

Hole Sponsorship - \$1,500

1 team of 4, Tee & Green Signage

Beverage Cart Sponsorship - \$1,500

1 team of 4, Name & Logo on Beverage Cart

Breakfast Sponsorship - \$1,000

1 team of 4, Recognition During Breakfast with up to 5 minute, Non-Branded Presentation

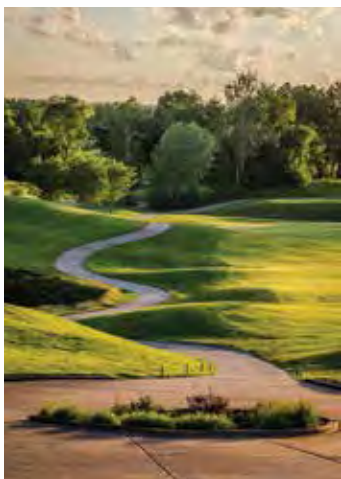
Team Sponsorship - \$600

1 team of 4

Corporate Sponsorship - \$250

Name & Logo on Event Banner

Names/logos of all sponsors will appear on the event banner.





Brothers HEALTHCARE

Rx + ∞ + ♥ = ∞

Welcome

Mimi, Anna & Noel to BROTHERS HEALTHCARE

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 ANNA MACDONALD: 760.540.3118 | annam@brothershealthcare.com
 NOEL MINOR, RN, BSN: 316.866.0114 | noelm@brothershealthcare.com

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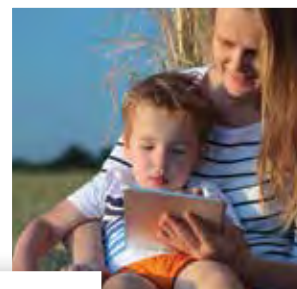
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When you use your existing **Amazon.com** account to shop through AmazonSmile, 0.5% of your eligible purchases will be donated to MHA. AmazonSmile is the same Amazon you know. Same products, same price, same service.

You Shop. Amazon gives.

Learn more or get started today!

Go to: <https://smile.amazon.com>



2019 National Conference for Women with Hemophilia & Symptomatic Carriers Being Visible: Hear Our Voices

November 1-3, 2019, Westin Hotel, Detroit Metropolitan Airport

Women who are eligible to join us will experience an amazing weekend learning from national expert health care providers, and have opportunities to connect with other attendees who each bring their own unique wisdom and experience of living with hemophilia.

- There is **NO CHARGE** for this weekend.
- To learn more, go to: hfmich.org/national-conference-for-women-with-hemophilia/
- **Questions?** Contact Patrice Thomas at pthomas@hfmich.org, 734.544.0015.

APPLICATION PROCESS OPENS IN JULY

Regional Sponsor



Community Lead Sponsor

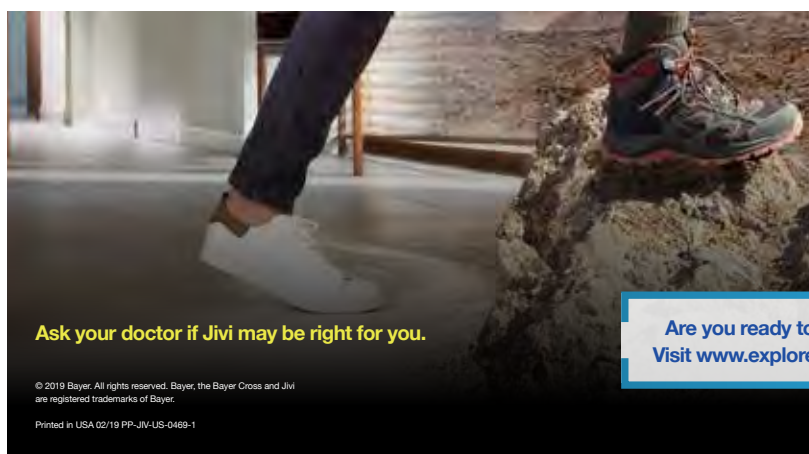



Community Sponsors



Sponsors as of
6.14.19. Additional
sponsors pending.

HFM (Hemophilia Foundation of Michigan) exists to enhance the quality of life for all affected by bleeding disorders. www.hfmich.org. HFM does not endorse any specific product or company.






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(recombinant) PEGylated-aud

LET'S GO

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Comparing Adherence and Physical Activity in Hemophilia A Patients

In a recently published study, a team of Italian investigators studied potential correlations between levels of physical activity and adherence to a prophylactic treatment regimen in a group of individuals with severe hemophilia A. The lead author was Ezio Zanon, MD, director of the Hemophilia Center from the University Hospital of Padua.

Zanon and his colleagues recruited from 14 hemophilia treatment centers across Italy, ultimately enrolling 42 individuals with severe hemophilia A for the 36-month prospective study, known as SHAPE. Participants included children (31.0%), adolescents (21.4%) and adults (47.6%), all of whom had been receiving prophylactic therapy with a recombinant factor VIII (rFVIII) product for a minimum of six months.

Physical activity levels were measured by the Hemophilia and Exercise Project (HEP)-Test-Q, an instrument for the assessment of subjective physical functioning in children with hemophilia and the Early Prophylaxis Immunologic Challenge (EPIC)-Norfolk Physical Activity Questionnaire, a questionnaire designed for the collection of self-reported physical activity behaviors. In addition, joint health was evaluated via the Hemophilia Joint Health Score (HJHS) which is designed for those joints most commonly affected by hemophilia-related bleeding, including the ankles, knees and elbows. Lastly, prophylaxis adherence was calculated by the ratio between the number of empty vials returned divided by the total number of vials prescribed.

Overall, 80% of the participants adhered to their prophylactic treatment regimen, including 83.3% of children, 77.8% of adolescents, and 78.9% of adults. In the year preceeding the study, 50% of the participants experienced at least one spontaneous bleed. This rate dropped in each of the subsequent years, to 34.4% in the first year, 31.3% in the second and 28.1% in the third.

The results showed that the type, frequency and impact of physical activities varied significantly amongst the three age groups. Participants' poorest performance fell under the "endurance" and "strength/coordination" categories. Adherent patients exhibited better joint scores and lost fewer school/work days than those non-adherent participants. Investigators found that highly adherent patients engaged more often in sports and other physical activities with moderate impact on joints, when compared to those with poor adherence.

"The results of this study showed high adherence to prophylaxis in our Italian population of hemophilia A patients, and this correlated with a significant reduction in bleeding events, number of target joints, and school/work days lost over time, and a steady improvement in performance during endurance sports activities," stated the authors.

The authors acknowledge that the study has limitations, including adherence data that is based on only a single FVIII product. They also recognize that while the study is small and that the sample size of non-adherent patients does not allow for a robust comparative analysis, it does pave the way for future studies to further examine possible correlations between adherence to prophylaxis and physical activity in hemophilia patients.

The study was appeared online in journal *Blood Transfusion*.

— Source: *Hemophilia News Today*,
June 17, 2019





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