CHAPTER *Factors*

SPRING 2019

Jefferson City, Missouri & Washington DC

ADVOCACY DAYS

Midwest Hemophilia Association

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LET'S GO

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FROM THE BOARD PRESIDENT

Change can be good.

change [CHānj] *verb*: make or become different; noun: the act or instance of making or becoming different. Synonyms: convert, transform, adapt, modify, reconstruct, remake, make over.

Some people would prefer not to have change in their lives. They enjoy routine, habits, and knowing what to expect. Others would say they enjoy change—it's a fresh start, a new look on life. I tend to lean on the side of welcoming change. It is an opportunity for something exciting, new and refreshing. It's a time to gratefully celebrate the past and move forward into different adventures!

Whether you are one who embraces change or resists it, change has come to Midwest Hemophilia Association and the bleeding disorder community. Let me take the time to explain.

In January, after 10 years of loyal service, the Executive Director of MHA resigned propelling the Board and I into the first steps towards change. The Board President took the lead in establishing new committees while reconstructing the existing ones: Advocacy, IT/Social Media, Events/Calendar, Communications, Grants/Fundraising, Camp Committee, and Member/Board Recruitment. Several Board members attended national training with NHF, Advocacy Days in Jefferson City and Washington D.C., and HFA Annual Symposium to gather the much-needed information to start in the direction of a positive transformation.

Then, in April, the Board President resigned. We were faced with an unexpected change. Again, an opportunity to grow and learn. The Board and I have had to step into roles and responsibilities new to our usual routine. We voted in a, mostly new, executive board, reassigned tasks and duties, started campaigns to update our community contact base and recruit board members, and attempted to keep the positive relationship with the HTC, chapter supporters, and industry donors. It hasn't been easy, but it's been positive!

Change has forced us to become better stewards of our responsibility to you, our community. It has given us a new awareness of the magnitude of work that goes into the day-to-day operations of keeping a non-profit alive and healthy. It has provided us the chance to improve our communication and transparency. It has motivated us to move forward, do better and embrace the change!

But we can't do it without YOU! We WANT you to be part of this change! We NEED you to be part of the transformation! This is your community, your chapter! We are here to serve you.

So…are you ready? Are you willing? Are you committed? We hope you are! In this newsletter, you will find several ways in which you can be an active part of the community, whether it is serving on the board as a short-term member, assisting on a committee, volunteering at an event, helping in the office with mailers, fundraising, seeking outside community donors, or supporting one another by attending events. There is a place for you!

I (we) look forward to stepping into this brand-new adventure together!

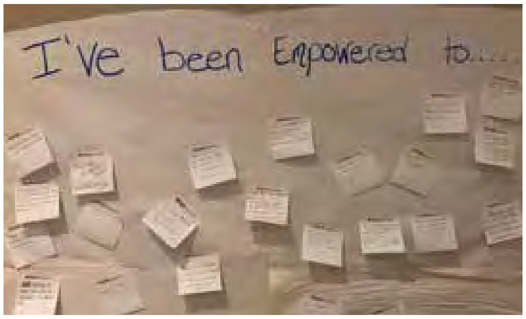
Sincerely,
Angela Brown
MHA Board President

QUICK NOTES

Women's Retreat held in Lake Ozark, MO

Midwest Hemophilia Association (MHA), in conjunction with Gateway Hemophilia Association (GHA) located in St. Louis, MO, co-sponsored a Women's Retreat on March 22-24, 2019. Held at The Lodge of the Four Seasons in Lake Ozark, MO, the retreat welcomed female members of MHA and GHA 18 and older who are caregivers of a person with a bleeding disorder or have a bleeding disorder themselves.

Over 30 women took part in the three-day event, which revolved around a theme of empowerment and focused on education, personal growth, networking and relaxation. The attendees had the opportunity to participate in several educational sessions, including Women Bleed Too, Advocating for Yourself, and Pain Management. During these sessions, the members discussed what needs are not being met for women with bleeding disorders and advocacy methods to help the community get its voice and information heard.



ABOVE: More than 30 women attended the Women's Retreat at The Lodge of the Four Seasons in Lake Ozark, MO on March 22-24, 2019. The event was co-sponsored with Gateway Hemophilia Association located in St. Louis, MO.

LEFT: Following the empowerment theme,, attendees posted their thoughts on what they have been motivated to achieve.

Going along with the empowerment theme, attendees also watched the 2018 movie "Made for More" by Rachel Hollis, CEO and founder of The Chic Site blog. The film is aimed to inspire women to believe in themselves to change the world.

Co-pay Accumulator Programs to be Limited in 2020

On April 18, 2019, the Centers for Medicare and Medicaid Services (CMS) released the final Notice of Benefit and Payment Parameters Rule for 2020. This rule is released each year to set policies for private insurance plans in the US. In the 2020 Final NBPP Rule, CMS finalized a policy that only allows plans to implement co-pay accumulator programs in limited scenarios – only for brand name drugs when there is a generic alternative, and only when an appeals or exceptions process has found that the brand name drug is not medically necessary. Co-pay accumulator programs essentially disallow co-pay assistance from counting towards a person's out-of-pocket (OOP) maximum. CMS has specifically said that in cases where there is no generic alternative, co-pay assistance should accrue to a person's OOP max. Since our treatments do not have generic alternatives, this rule should significantly reduce the effects of co-pay accumulator programs for the bleeding disorders community starting in 2020.

The National Hemophilia Foundation (NHF) has been leading efforts to fight co-pay accumulator programs since their inception, serving on the steering committee of the All Copays Count Coalition, speaking at and hosting webinars for national and regional employer coalitions, as well as advocating in Washington, DC, state houses across the country, and directly with payers who have implemented or considered implementing these policies.

NHF had the opportunity to meet

with CMS last fall, along with other members of the All Copays Count steering committee, and again just as NHF in early in 2019, to discuss the issues surrounding copay accumulator programs. Our advocacy efforts were critical in helping CMS understand this issue and helped lead them to implement this new policy. NHF will continue its efforts to ensure that all people with bleeding disorders have access to the treatments they need to lead healthy, productive lives regardless of where they live or what type of insurance they have.

If you would like to become more involved in local and national advocacy issues for bleeding disorders, go to pages 8 and 9 of this issue for more information.

– Source: National Hemophilia Foundation website hemophilia.org. April 19, 2019

21st Annual MHA Golf Tournament

Mark your calendars now to attend 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. Registration forms can be found on the MHA website at *MidwestHemophilia.org*. Deadline for registration is August 24, 2019.

This year's tournament will be held at a new location, WinterStone Golf Course in Independence, MO. The 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.

The tournament committee is currently securing sponsorships for the event. Available opportunities include Title Sponsor, Lunch Sponsor, Foursome Photo Booth Sponsor, Golf Cart Sponsor, Hole Sponsor, Beverage Cart Sponsor, and Breakfast Sponsor. For more information about the tournament or to become a sponsor, contact MHA Golf Tournament Fundraiser Chair David Moss at *david.moss@grifols.com*.

Calendar of Events

June 8, 2019
MHA Trivia Night
Parlor KC • Kansas City, MO

June 15, 2019
Western Kansas Education Event
Guymon Petro Restaurant • Dodge City, KS

July 29 – August 2, 2019
29th Annual Summer Camp
Lake Doniphan Conference and Retreat Center
Excelsior Springs, MO

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

Jefferson City, Missouri & Washington DC

ADVOCACY

In March, members of Midwest Hemophilia Association joined forces with advocates from across the country to voice concerns of the bleeding community to state and national government officials. Participants wore red ties to bring awareness during the Bleeding Disorder Advocacy Days.

Missouri residents visited legislators at the capitol in Jefferson City, MO on March 7, 2019. During the event, 38 attendees from 19 families visited with state officials. Throughout the day, they completed 35 appointments with representatives to discuss bleeding disorders. Forty-three families attended a Advocacy Training dinner for attendees and a Teen Advocacy Training the night before at the Capitol Plaza Hotel in Jefferson City.

Six Missouri residents and one Kansas resident travelled to Capitol Hill in Washington, DC on March 27-29, 2019 to promote awareness, joining 400 others from almost all 50 states. MHA members met with newly-elected Senator Josh Hawley from Missouri for a very positive meeting on the topic.

While on The Hill, advocates asked for continued financial support for federal hemophilia programs. Federal monies fund hemophilia treatment centers and the 340B program, which support comprehensive care, plus the CDC Division of Blood Disorders, which supports surveillance and prevention activities. Funds from the national level also go to finance high priority research on bleeding disorders and complications associated with the diseases. They also requested support for HR1010 to rescind the expansion of short-term health plans which weaken the insurance market and could force higher prices on those who have chronic medical conditions.


Missouri

Washington, DC

DAYS


Missouri


Washington, DC


Missouri


Missouri


Missouri


Missouri

We Need

We are accepting short-term board member applications. We have temporarily modified the board bylaws to help us through the transition of hiring a new Executive Director and ensuring we maintain our current event and fundraising calendar. If you, or someone you know, are committed to the time and energy needed for a successful changeover, please go to the MHA website: midwesthemophilia.org, hover of "Become a Member" tab, scroll down & click on "Board Member App". Print the application, fill it out, and mail it to the address on the form. Someone will contact you to ask some additional questions if needed, and following a vote, we will let you know the outcome.

Those approved for a "short-term" board position will begin immediately following a majority vote of "yes". The term will end December 31, 2019. However, if continued participation as a "full term" board member is of interest, you may indicate your interest prior to December 31, and it will be considered at the appropriate end-of-year board meeting.

You DO NOT have to be a board member to serve on a committee, volunteer at events, and/or raise money for the chapter.

Please consider joining us to promote awareness and education. Board Member applications can be found on our website *midwesthemophilia.org* under the "Become a Member" tab. For questions, send an email to *info@midwesthemophilia.org* or you may contact any of the Board Members listed on page 3 of this issue for more information.

To Become a Board Member...

- **Board members are strongly encouraged to be actively part of at least one committee.**
- **Board members may not miss more than three meetings per year.**
- **Board members are expected to contribute and/or donate via fundraising a minimum of $500 per year.**
- **Board members do not have to have a bleeding disorder or be part of the bleeding disorder community to apply.**

COMMUNITY CONTACT CAMPAIGN

Here is your first opportunity towards change! 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.

YOU!

Ways You Can Become Involved

Interested in volunteering or being a committee member? We have several opportunities for volunteers and committee members. Please contact the person listed next to the committee and/or volunteer opportunity.

- **ADVOCACY COMMITTEE**
  Nora Ancel
  nora.e.ancel@gmail.com
  Raise awareness through various campaigns (ex: Red Tie Challenge); help plan advocacy education, attend state level advocacy days

- **COMMUNICATIONS**
  Shari Keeney
  skeeney9@comcast.net
  Submit articles for newsletter related to the community; strong writing skills recommended

- **GRANTS/FUNDRAISING**
  Angela Brown
  angela.brown@midwesthemophilia.org
  Assist in helping find resources/donors outside community, lead by example in actual fundraising (walk, trivia, and/or golf); attend/volunteer at fundraising events

- **MEMBER/BOARD RECRUITMENT**
  Kim Rosenfelt
  KRosenfelt@SBCGlobal.net
  Assist with development of member/board recruitment events; assist with new member breakouts sessions (ex: Chapter Ambassador)

- **EVENTS VOLUNTEER**
  Angela Brown
  mhaevents@midwesthemophilia.org
  Set-up/tear-down at events, registration, room monitor/surveys/speaker introductions, childcare, offsite chaperones, Chapter Ambassador

- **OFFICE VOLUNTEER**
  Nora Ancel
  nora.e.ancel@gmail.com
  Stuffing envelopes, sending mailers, item inventory, community contact campaign and updating database

- **CAMP VOLUNTEER**
  Luke Saulsberry
  mhacampdirector@gmail.com
  Provide assistance needed during camp by doing various tasks related to camp activities, registration and food service.

Shop through amazonsmile to support Midwest Hemophilia

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.

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Learn more or get started today!

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

21st Annual

MHA GOLF TOURNAMENT

September 13, 2019

Check in at 7:00 a.m. • Tee Time at 8:00 a.m.

WINTERSTONE GOLF COURSE
17101 E. Kentucky Road
Independence, MO 64058
winterstonegolf.com

NEW LOCATION!

For more information, visit https://midwesthemophilia.org/events/mha-golf-tournament-2/

Start Forming Your Team NOW!

WALK WITH US! MHA NHF HEMOPHILIA WALK

Unite

for Bleeding Disorders

SATURDAY, AUGUST 24, 2019

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

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

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

To register and start your team TODAY, visit

www.UniteForBleedingDisorders.org

Click on "Find a Walk" and search for Walks in Kansas

Midwest
Hemophilia
Association

The **Midwest Hemophilia Association** (MHA) is a non-profit organization dedicated to promoting awareness, providing group support, educating, and facilitating communication for the bleeding disorders community of western Missouri and eastern Kansas. Proceeds from the tournament help support MHA educational seminars, annual advocacy conferences, support groups and summer camp.

HELPFUL NUMBERS

KANSAS CITY REGIONAL HEMOPHILIA CENTER

1-816-302-6869 • 1-800-236-1713

PEDIATRIC: Dr. Shannon Carpenter
Dr. Brian Wicklund • Dr. Michael Silvey

ADULT: Dr. William Jennings • Dr. Jill Moormeier

NURSE PRACTIONERS: Rebecca Coney, DNP, APRN, FNP-C
Lucy Carter Reardon, RN, MSN, APRN, FNP-C

CARE COORDINATORS: Stacy Long, RN, BSN, CPHON
Rebecca Herder, MSN, RN, OCN, CNL

SOCIAL WORK: Katie Foote, LSCSW, LCSW, OSW-C

UNIVERSITY OF MISSOURI HOSPITAL AND CLINICS HEMOPHILIA TREATMENT CENTER

1-573-882-9355

NATIONAL HEMOPHILIA FOUNDATION (NHF)

1-800-42-HANDI • www.hemophilia.org

Summer Hot Topics:

BICYCLE SAFETY

Children's Mercy Center for Childhood Safety and Injury Prevention list Pedestrian Injury as one of the top 5 preventable injuries occurring to children. Pedestrian injuries include walking and biking injuries. It's important to review proper roadside safety such as signaling, bright or reflective clothing, eye contact when possible and to use crosswalks when available.

Bicycle helmets should be mandatory for EVERYONE. By law, many states require the use of a helmet. While the law is not state wide, county law in both St. Louis County, MO and Laurence, KS require those 1-16 years to wear a helmet while engaging in wheeled sports. The HTC considers "wheel sports" to be: bicycle, tricycle, scooter, strider, hoover board, skateboard... you see where we're going?

The best way to encourage compliance is to lead by example; parents and siblings get those helmets out! At your next comprehensive visit ask your HTC team for more information on helmet safety!

— Stacy Long, RN, BSN, CPHON

Helmet Fitting: "Eyes, Ears, Mouth!"

EYES:
Look up and see the rim of the helmet.

EARS:
Side straps make a "V" over your ears.

MOUTH:
Chin strap cannot be lifted over your chin.

Hemophilia Treatment Center (816) 302-6869
Center for Childhood Safety: (816) 234-1607

Researchers Look at Clinical Outcomes in FXIII Babies

Individuals with factor XIII deficiency (FXIII), a very rare inherited bleeding disorder, may experience a number of symptoms including umbilical cord bleeding, bruising, nose and mouth bleeds, plus heavy menstrual bleeding and repeat miscarriages in affected females. Spontaneous hemorrhaging in the brain, one of the most life-threatening of bleeding complications, occurs in approximately 30% of FXIII patients.

Neonates (infants less than four weeks old) with FXIII are susceptible to brain and other bleeds during the delivery process. Researchers in Iran, a country which experiences disproportionately higher rates of FXIII cases when compared to most other nations, sought to understand the risk factors and clinical features of these patients in the hopes of forestalling serious bleeding complications in the future. The lead author of this study was Majid Naderi, MD, Department of Pediatrics Hematology & Oncology, Ali Ebn-e Abitaleb Hospital Research Center For Children and Adolescents Health, Zahedan University of Medical Sciences in Zahedan, Iran.

Naderi and his colleagues performed a retrospective, cross-sectional analysis of 27 neonatal patients who had experienced bleeding events and who had been diagnosed specifically with FXIII A-subunit (FXIII cases are designated either subunit A or subunit B.) Most FXIII cases are associated with a causal mutation in subunit A. Investigators looked at patient data, demographic information, family history, method of birth delivery, clinical data, and imaging history. All patients received treatment with FXIII concentrate upon first bleeding event, followed by FXIII prophylaxis.

All 27 patients experienced umbilical cord bleeding. Clinical evidence of central nervous system (CNS) bleeding was found in nearly half of the patients (13, 48.1%). Both seizure and delayed umbilical stump separation occurred in five patients (18.5%). Three patients experienced hematoma, and one had ecchymosis, a skin discoloration caused by ruptured blood vessels that cause blood to escape into tissue.

Their analysis also indicated that 19 of these patients (70.3%) had a family history of “suspicious” FXIII deficiency-related deaths and that all 27 patients had the same specific FXIII-related mutation.

Investigators also reported that a history of CNS bleeding was not significantly associated with clinical presentation, familial FXIII deficiency history, birth delivery method, gender, or age. CNS bleeding did however show a slightly significant relationship with the mean number of suspicious deaths related to FXIII deficiency in a patient’s family history.

Naderi and his fellow investigators conclude by recommending that prenatal diagnostic screening should be conducted in any cases where there is a positive family history of factor XIII deficiency and that prophylaxis with a FXIII product be employed to prevent bleeding complications in affected neonates.

The study, “A Retrospective Study on Clinical Manifestations of Neonates with FXIII-A Deficiency,” was published in the journal Blood Cells, Molecules, and Diseases.

— Source: Hematology Advisor, May 2, 2019

The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

Genentech | Hemophilia A
A Member of the Roche Group

Let's put science to work

GenentechHemophilia.com

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Pfizer Hemophilia Connect

For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday from 8:00 AM to 8:00 PM Eastern Time.

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Pfizer

MOVING?
NEW ADDRESS?

Update your contact information by visiting *MidwestHemophilia.org* and clicking on the “Become a Member” tab. Once complete, click JOIN and you’re done!

Midwest Hemophilia Association
PO Box 412866
Kansas City, MO 64141