CHAPTER Factors

WINTER 2019

You're Invited

ADVOCACY 2020

**Midwest
Hemophilia
Association**


ARJ Infusion SERVICES
Where Caring is the
Ultimate Factor.

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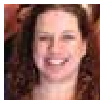

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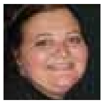

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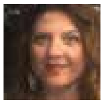

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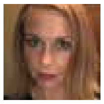

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FROM THE EXECUTIVE DIRECTOR

I want to begin by saying "thank you" to the MHA Board of Directors for the opportunity to serve the Midwest Hemophilia Association bleeding disorder community as the new Executive Director. I also want to say "thank you" to community members who have shared words of encouragement and congratulations. I consider the position an honor and privilege and hope to represent you, our chapter members, in the best way possible.

With that said the first goal of the Board has been to improve communication to our membership and industry partners of events, advocacy, and programs relative to the bleeding disorder community. If you are on our mailing and email lists, follow us on social media, visit our website and/or attended one of our events in 2019, you probably have noticed a significant increase in information. This will continue. If you run into someone who is not getting information about the chapter, encourage them go to the website and click on the "become a member" tab. This is the first step in updating our database. They can also follow us on Facebook, Twitter and Instagram (see back page of this newsletter).

Second, the goal is to better engage the community during events so we can hear your thoughts and ideas. We can do this by making ourselves visible, available, and approachable. It's important that you recognize mine and the Board's names and faces when you see us, that we are present and engaged at activities, and we are listening and hearing what you have to say or share.

With the second goal in mind, in 2020, we will be implementing 'Town Hall' meetings in as many of our outreaching areas as possible. At those meetings we will be discussing the questions, "What are we doing well? What can we improve? What are the needs/wants of the community? And How can we best meet those needs/wants?" We will also be sending out surveys to capture the basic demographics of our membership and request your opinions on a variety of topics. This will help us reach as many people as possible as well as reach those who may not be able to attend a town hall meeting and it will help us determine the kinds of topics/discussions we should be providing.

Finally, with the changes in how and what our industry supporters can sponsor our chapter programs and events, our last goal is to develop a strategic plan for continued funding. This would include applying for grants and/or resources outside of industry, finding new donors, adding new fundraising opportunities, increasing participation in and outside the community at current fundraisers (Trivia, Golf, & UNITE Walk), and making sure we continue to be good stewards of the finances we have.

In closing, it is important to understand that the Board and I are here to serve you to the best of our abilities. If you have questions, comments or concerns, please feel free to contact us. I look forward to having an open dialogue about how we can best serve you!

Sincerely,
Angela Brown
angela.brown@midwesthemophilia.org

QUICK NOTES

Garcia Attends Women's Conference

Local MHA Chapter Member Alicia Garcia attended the 2019 National Conference for Women with Bleeding Disorders and Carriers hosted by The Hemophilia Foundation of Michigan. The event was held November 1-3, 2019 at the Westin Hotel, Detroit Metropolitan Airport. This year's theme was "Hear Our Voices: Women with Hemophilia." Alicia writes:

This is the second time that I've attended. I feel like it's an honor to go every year. I met new friends and there were a lot of educational opportunities throughout the weekend. This year we made a quilt patch for a quilt that was personalized to us and all us women. In the class, we were able to put a patch on the quilt that will travel around and be seen at other events such as this. It was so neat. Every year I take a lot of useful information home so I can advocate for me and my family. I feel like that is very important especially because I live in southwest Kansas and there's not many HTC's that are close to home. Being able to hear empowering information on my bleeding disorder and what my body goes through as a woman with hemophilia is amazing. I've met several women at these conferences that I can relate to and I'm not alone! I have hemophilia sisters from all over the United States. Thanks to Hemophilia foundation of Michigan.

– Alicia Garcia, MHA Member

Tyson (left) and Jaiden represented MHA at CSL's Gettin' in the Game.

MHA Represented at National Contests

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national golf, baseball, and swimming competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game Athletes, who themselves have been diagnosed with bleeding disorders, such as hemophilia and von Willebrand Disease.

During the program participants have the opportunity to:

- Take part in either golf, baseball, or swimming activities to learn the fundamentals and enhance their skills in that sport.
- Learn about the importance of physical fitness in managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form.
- Show off their golf, baseball, or swimming abilities in a national competition with fellow participants from around the country.
- Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.

Josh Ancel was the 2019 Volunteer of the Year. MHA recognized him for his willingness to be available and respond to needs at all times and hours of the day, his many hours of assistance with our IT projects (emails, social media, website, etc), and his enthusiasm doing it! Thank you Josh!

The Votes Are In!

MHA realized we needed to spread out fundraising events in 2020. We considered seasons, school/vacation calendars, national events, and surrounding chapters' events to avoid overlap.

Thank you to all who participated in the Survey Monkey to determine the date of our local chapter's UNITE For Bleeding Disorders Walk. The votes have been tallied and the date for the 2020 MHA Walk will be Saturday, June 13!

Turn to page 14 for photos of the 2019 Walk!

Great Educational Opportunity for Wichita Attendees

What a great day we had at the Wichita Education Day, Saturday, October 19, 2019 at the Drury Broadview Hotel in Kansas. Adult education included learning how to become a wise consumer presented by NHF Staff Member, Sarah Waite-Ardini. Jennifer Johnson from Acreddo helped youth learned about how their blood works. Childcare was provided by Royal Family Kids. Attendees were given the opportunity to mingle and network with each other as well as our industry sponsors and even played a round of "Get-to-Know-You" BINGO! Lunch and tickets to the Sedgwick County Zoo were provided to all attendees. This is an annual event and we hope YOU will join us next time!

Wichita Education Event attendees enjoyed fun activities while learning about bleeding disorders. Tickets to the zoo were distributed all participants.

Thank you to our 2019 Industry Sponsors

Accredo

Accurate Rx

Aptevo

ARJ Infusion Service

BioEthics Advantage

Bayer

Niki Bird

Bob Eschbacher

Briova Rx

Brothers Healthcare

Central Plains Cement Company

Children's Mercy 340B
Factor Program

CSL Behring

CVS Specialty

FactorOne Source

Flicsha Roberson

Genentech

Grifols

Innovative Infusion Specialists

KC Nannies

Kendra Scott

Novo Nordisk

Paragon

Pfizer

R.A. Long Foundation

Sanofi

Soleo Health

Sporting KC

Superior Biologics

Takeda

QUICK NOTES

2020 EVENTS CALENDAR

January 7-12
Generation IX Leadership Retreat

January 25
Springfield Town Hall Meeting

February 26-28
NHF Washington Days

February 29
KC Town Hall Meeting

March 4
Missouri Advocacy Training Dinner

March 5
Missouri Advocacy Day

March 20-22
FAB Conference
Females and Bleeding Regional Women's Retreat with MHA, GHA, HOI, & NE Chapter

April 2-5
YETI Conference

April 4
Dodge City Town Hall & Education Day

April 5
Wichita Town Hall (tentative)

April 23-26
HFA Annual Symposium

June 13
UNITE For Bleeding Disorders Walk

July 18
Springfield Education Day

July 26-31
Camp Wilderness

August 4-8
NHF Bleeding Disorder Conference
Atlanta, GA

September 18
22nd Annual Golf Tournament

September 19-20
28th Annual Family Education Weekend & Awards Ceremony

October 24
Trivia Night Fundraiser

November 7
Wichita Education Day

December TBD
Holiday Party

The Newcombs attended the 2019 NHF Annual Meeting held in Anaheim, CA. Stacy Newcomb won the trip at MHA's 2018 Family Education Weekend.

Family Education Weekend Raffle Winners

At last year's Family Education Weekend, Mike and Stacy Newcomb held the winning raffle ticket for a trip to the 2019 NHF Annual Meeting. They traveled to the meeting in Anaheim, CA on October 3-5, 2019. She writes:

First off, we are very thankful to the Chapter for raffling off the amazing prize of the trip for two to NHF. We brought my mother and daughter along for the trip as well. The lunch on Thursday was very fun and interactive and started out the conference perfectly. In fact Alex was on stage and was part of the show.

Alex (17) and Madie (13) both attended the Teen Track program and I was very excited to see this type of programming for the older kids. Alex is beginning the process of transitioning into adulthood and there were several sessions that talked about that process. He said they talked about how to apply for jobs, what do you tell an employer and what to expect from the adult HTC. Madie got the most out of connecting with other siblings her age who can understand the sibling point of view. She also was able to take away some valuable information regarding applying for jobs as well. The kids also had a session on identity and mental health which is so important for today's kids. The kids mentioned that they missed the offsite activity, however they did enjoy their sessions and even won prizes for attending a specific amount of sessions.

Mike, my mom and myself attended several sessions on the advancement of treatments, gene therapy, joint issues and the all important and scary sessions on insurance. My biggest take away from the insurance session is document, document document and keep good records of everything. The session on treatment advancement and gene therapy is usually a tad over my head but gives me a starting point to talk to the hematologist.

The exhibit hall is a wonderful place to talk to all the companies, meet some of the area representatives, and the all important swag! Alex made some very good connections with representatives of the companies and he is learning how to be a good consumer.

The final night event is a great time to connect with friends that you may only talk to online or in facebook groups.

Again a big thank you to the Chapter for the trip!!! It was so hard to come back home to cold temps!

— Mike, Stacy & Alex Newcomb and Madie & Kathy Armour

MHA Adds Two New Board Members

MHA recently welcomed two new members to its Board of Directors, Mareena Snarey and Cody York.

Mareena Snarey resides in Monett, MO with her husband, James and four children. She has been an active member of MHA for 10+ years. She worked professionally in web marketing where she ran email campaigns for a promotional products company for US and international customers in 15 countries. She has served as both Treasurer and President of her local Parent Teacher Organization. She organized the PTO 5k Cub Run Fundraiser and has served on an HOA board. She is currently serving as the President of her church's women's group in her local congregation and has been in this position for nearly 3 years.

Cody York is from Neosho, MO, but resides in Springfield, MO where he currently is completing his third year of pharmacy training at UMKC School of Pharmacy. He studied Biochemistry at Missouri Southern State University and General Studies at Crowder College. After meeting someone with hemophilia, Cody began volunteering in the bleeding disorder community at GHA's Trivia Nights MHA and GHA's Family Education Weekends, Camp Notaclotamongus, GHA's Give Back Event, and attended the 2018 World Congress in Scotland. He looks forward to broadening his knowledge of bleeding disorders and bringing new ideas, contacts, and networking to the organization.

We're On the Move…

We strongly believe our chapter is first and foremost made up of people… not an office space. There have been some well-meaning questions on when and if the new Executive Director will be moving to the Kansas City area. It is one we are glad to answer now and can best be answered with a little bit of history.

About a year ago at the end of 2018, discussions relative to the office being rented at 8900 State Line Road began when the former ED and Board knew the lease would be ending in December 2019. The initial talk of whether to keep the current office or find another space was essentially due to the non-sensical rising cost of rent as it was written in the current contract and the need for additional storage space of our re-usable materials (signage, tables, chairs, exhibit table resources, childcare games/activities, etc.).

While not out of mind, discussion on this topic was put on hold in March after changes in leadership occurred and our focus needed to shift to keeping the chapter running smoothly until a new Executive Director could be hired. However, it was determined that a new space was most likely needed.

When the new ED was offered the job at the end of July, the board made allowance, at the new ED's request, not to require a relocation until after May 2020 for personal/family reasons. This would also allow more time to determine:

1. if an actual office space was needed or if expenses could be saved by working from a home office in the Kansas City area
2. allow more time to find a better, more affordable office in the event the current lease ran out and nothing had yet been found,
3. and demonstrate the success of possibly moving the office closer to the ED.

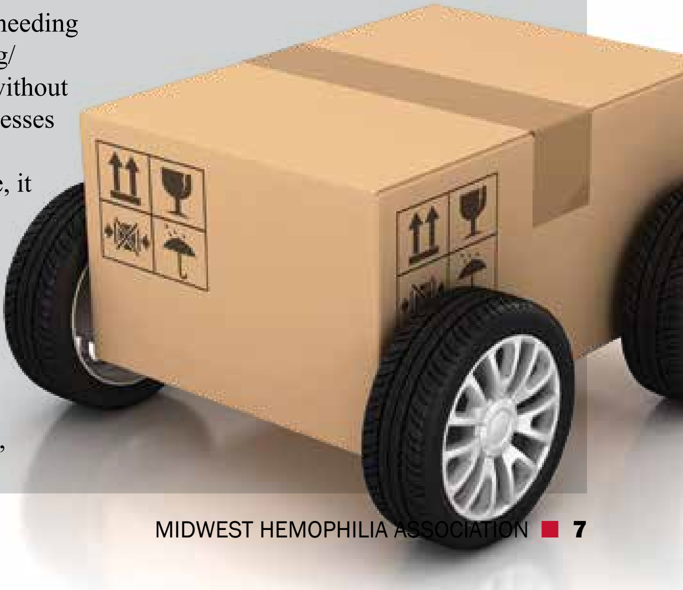
Several options, including staying at the current building location, looking for offices in the surrounding Kansas City area, and moving the office to Springfield were considered. Much thought, discussion and weighing of pros and cons was done by everyone.

From a physical perspective, it was decided that a business office space is needed, rather than a home office. While this seemed like the best option (no rent or associated rent costs) this was ruled out for the reasons of needing a business address where funding/checks could legally be mailed without ethical questions and it also addresses the issue of storage space.

From a financial perspective, it was determined that MHA could improve operating efficiency and decrease associated operating costs so more dollars go towards our mission by leasing office space outside of the Kansas City area.

From a logistics perspective, it was proven that the job itself has been successfully completed from the Springfield area. There was very little disruption in the day-to-day operations of MHA by having the work being done there. And what little disruptions there were, can and will be solved by relocating.

Therefore, we are excited to announce the hunt of finding an office space in the Springfield, Missouri, area has begun. We are keeping the P.O. Box 412866 Kansas City, MO 64141 address for the foreseeable future. The office phone (816) 479-5900 will remain on and mail will still be received at the 8900 State Line Rd, Suite 411, Leawood, Kansas 66206 address until December 31, 2019. Mail will be forwarded after that date. The best phone number to call to reach a live person is: 314-952-6265. All emails remain the same.



You're Invited
TO ADVOCACY 2020

LET YOUR VOICE BE HEARD!

Join us during these two great events to advocate for the bleeding disorders community. Remember that budgets and viewpoints can be changed if enough people speak up and show that they care. You are the most passionate, knowledgeable expert on the subject. Who better to tell them than you? So speak up, loudly and frequently!

NHF WASHINGTON DAYS
FEBRUARY 26-28, 2020

We are delighted to invite you to attend NHF's Washington Days to be held Wednesday, February 26 through Friday, February 28 2020, at Hyatt Regency Washington on Capitol Hill. General registration opened November 20, 2019. Please note that each member of your family that is attending needs to have a completed registration. Register at

www.hemophilia.org

Registration deadline is Friday, January 24th.

The NHF Public Policy Team is working diligently to finalize what issues will be prioritized in February. They are closely monitoring various legislative and policy opportunities as they prepare for their event in February. NHF will be hosting two webinars again this year to prepare advocates for success on Capitol Hill. As they did this year, one will be targeted to new participants, and one will be structured to benefit more seasoned advocates. They will share the dates and times of the webinars as soon as possible. They will be made available to anyone who cannot participate at the appointed date and time. MHA will do our best to share these on our website and/or via email.

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders
WASHINGTON DAYS

MISSOURI BLEEDING DISORDERS ADVOCACY DAY
THURSDAY, MARCH 5, 2020

This is your opportunity to advocate directly with your elected officials and for the bleeding disorder's community of Missouri. Sharing your story with legislators is an important and an easy way to be part of the solution to the challenges facing the bleeding disorders community.

Registration deadline is Friday, January 24th.

There will be an Advocacy Training dinner for attendees and a Teen Advocacy Training the night before, Wednesday, March 4th, at the Capitol Plaza Hotel in Jefferson City. Registrants will receive more information as we get closer to the event. Register at ***gatewayhemophilia.org/events/mo-lobby-day/***

Travel Scholarships available to Missouri consumers traveling over 100 miles one way.

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GATEWAY HEMOPHILIA ASSOCIATION

Midwest
Hemophilia
Association

Introducing the new ED: *Angela Brown*

Angela Brown was selected as Executive Director of Midwest Hemophilia Association in July by the Board and hiring committee and officially began on September 1, 2019. Angela resides in Ozark, Missouri, with her husband Matt, and four children, Spencer, Jasmine, Cadian, and Myra. She is an active member and volunteer at her church, has been a foster parent and homeschool mom, and enjoys serving others.

Angela Brown

She attended Evangel University earning a BS is Elementary and Special Education and taught for 7 years as a special education teacher at both Ozark Upper Elementary and Ozark High School. After resigning from teaching to stay home with her oldest for three years, Angela was hired as a part-time consultant for a midwest division of a specialty pharmacy. Using her knowledge and experience with IEPs and 504s, she assisted families with their health and school-related needs to improve their experiences and communication with school personnel. She eventually was hired full time and assisted the company in developing quality relationships and service with the bleeding disorder community, chapter leaders and other industry representatives.

Angela grew up in Kansas with three younger sisters and a younger brother who was diagnosed with a bleeding disorder at nine months old when he had a mouth bleed. He was the first in the family to be diagnosed. Treatment and access to care was very different then. Prophylactic treatment and infusion nursing care was not the norm. Admittedly, she gained a whole new perspective when her son was also diagnosed with a bleeding disorder. Angela explains that her family initially faced many of the common challenges: misdiagnosis, doctors with little knowledge of bleeding disorders, long ER visits, and fear of the unknown. She and her husband found hope, peace of mind, freedom and independence, however, when they were introduced to the local and national chapters for bleeding disorders and began to attend events provided by MHA.

Angela has been a member of MHA for over 15 years, working in several difference capacities: participant, Camp Wilderness volunteer and girls counselor, walk volunteer, fundraiser, board member, and Springfield Education Day and FEW event planner. She has also participated in advocacy for bleeding disorders through state and national Advocacy Days with MHA, GHA, and NHF. She has collaborated in the development and execution of GHA's Camp Notaclotamongus, and been a girls camp counselor at Camp Bond with Oklahoma Hemophilia Foundation and James River Church Kids Camp. She was the recipient of the Volunteer of the Year Award from Gateway Hemophilia Association in July 2017.

She strives to pass along the knowledge and resources that have benefited her family as well as sharing up-to-date information on product and treatment options, insurance information, and other related health issues. She believes this information is helpful to newly diagnosed families, imperative for maintaining support networks to experienced families, and essential to sustain out future generations. Angela's goal as Executive Director is to continue to provide the bleeding disorders community with tools and resources through educational events, outreach groups, advocacy leadership, and summer camp.

Above: Angela joins other members of the Missouri Bleeding Coalition to discuss access to skilled nursing facility care for hemophilia patients. Left: Angela with Dr. Shannon Carpenter and Dr. Brian Wicklund at the 2019 Family Education Weekend awards ceremony held on September 15, 2019 in Olathe, KS.

Family Education

This year's annual Family Education Weekend kicked off with the roll out of our new chapter brochure themed, "Welcome! You Belong Here"! Over 200 adults and children (including 10 NEW community families!) and 22 industry partners and sponsors convened over the 2-day weekend in September at the Embassy Suites by Hilton in Olathe, Kansas.

Families started Saturday morning with registration and the open exhibit hall where they connected with new and old friends, manufacturers, specialty pharmacies, and representatives from the National Hemophilia Foundation followed by the Opening Welcome and lunch.

A variety of educational topics were offered both Saturday and Sunday for adults including von Willebrand Brands & Women's Reproductive Issues, Healthy Aging, The Science of Optimism, Gene Therapy, Evaluating Your Insurance, Pain Matters, and a new breakout session for our Spanish community. Other sessions included NHF's Artistically Speaking, an interactive, hands-on experience and their MyBDC Presentation. During the women's breakout session, ladies discussed in round-table format what it takes to be M-Powered while the men's breakout session heard from a featured community speaker about how "Change Can Be Beneficial".

The Teens had plenty to do as well on Saturday with off-site activities and lunch at PowerPlay. On Sunday they heard two educational presentations: The Road to Independence and Change & Resilience.

Not to be forgotten were our youth and childcare programs. Youth, grades K-5th, also went off-site to explore the Kansas City Zoo on Saturday. Their education included a hands-on learning experience called, Factor is Gold, 'blood-slime' included! KC Nannies provided amazing playtime, activities, and games for the "littles" under five years of age at the hotel.

Saturday evening dinner and activity took place for all attendees at Dave & Busters with plenty of food and fun for everyone.

The weekend ended by noon on Sunday with the annual raffle and 2020 NHF Trip Drawing as well as our annual Awards & Recognition Ceremony where we celebrated our academic scholarship winners for the 2019-2020 school year, the top UNITE walk fundraisers, golf tournament winners, Camp Wilderness "Big Stick" recipients, the 2019 Volunteer of the Year, and recognized Dr. Brian Wicklund for his service to our community with a Lifetime Recognition trophy as he plans to retire in 2020.

Adding our Awards & Recognition Ceremony to FEW began last year. With increasingly low attendance to the awards night over the past few years, the Board felt that incorporating it into our largest-attended event would bring the best recognition and opportunity to celebrate the accomplishments of the chapter's community members. We hope that it will inspire everyone!

THANK YOU TO OUR FEW SPONSORS

Bayer • CVS Specialty • Genentech • Sanofi • Pfizer
Soleo Health • Takeda • HPC Specialty Pharmacy
National Hemophilia Foundation • Accredo • Accurate Rx
Aptevo Therapeutics • ARJ Infusion Services
BioEthics Advantage • Brothers Healthcare
Children's Mercy 340B Factor Program • CSL Behring
Factor One Source • Grifols • Novo Nordisk
Paragon, • Superior Biologics

Weekend 2019

21st Annual MHA Golf Tournament

MHA welcomed 26 golf teams hit the course at the 2019 annual golf fundraiser held on the beautiful Winter Stone Golf Course in Independence, MO on September 13, 2019. Over $15,000 was raised to support our MHA chapter! Thank you players and sponsors for your support!

Participating teams were: Bayer, Team Moss, Novo Nordisk, CMH, Blue Cross, Butler Brothers, Soleo Teams 1 & 2, Ajilon Healthcare Teams 1,2, & 3, BioEthics Advantage, Diplomat-Accurate Rx, Team Dudley, Aptevo, Summit Interiors, ARJ Teams 1,2,3,4, & 5, CSL Behring, Superior Biologics Teams 1, 2 & 3 and Team BMRXRAY1.

Save the Date!

22nd Annual MHA Golf Tournament
September 18, 2020

Thank you to our sponsors!

$1,000 BREAKFAST SPONSOR
Novo Nordisk

$2,000 GOLF CARTS SPONSOR
BioEthics Advantage

$1,000 HOLE SPONSORS
Bayer
CSL Behring
Soleo Health

$1,500 BEVERAGE STATION SPONSOR
Soleo Health

$250 CORPORATE SPONSOR
BioEthics Advantage

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.[3]

- 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.

Shire

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.

Patented: see https://www.shire.com/legal-notice/product-patents

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Unite
for Bleeding Disorders

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SAVE THE DATE!

JUNE 13, 2020

MHA's UNITE For Bleeding Disorders Walk

Camp Wilderness

MHA's Summer Camp again was a huge success! The event hosted 65 campers at Lake Doniphan in Excelsior Springs, MO on July 29 through August 2, 2019.

This year's theme of the Oregon Trail was carried out by 55 volunteers, made up of counselors, CITs (counselor in training) day volunteers, night staff and med shed. Teams of campers worked together to build "wagons" and complete an obstacle course, both designed to go with the theme. A variety of activities, were also available, including archery, fishing, hiking, crafts, sports, movie night, campfires, and pool time.

All campers also participated in infusion clinic sharpening their skills related to getting their medications.

Thank You

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"Females And Bleeding" Conference

March 20-22, 2020

Honey Creek Resort in Moravia, IA

Open to all women ages 18+
within the MHA, GHA, HOI, and Nebraska chapters

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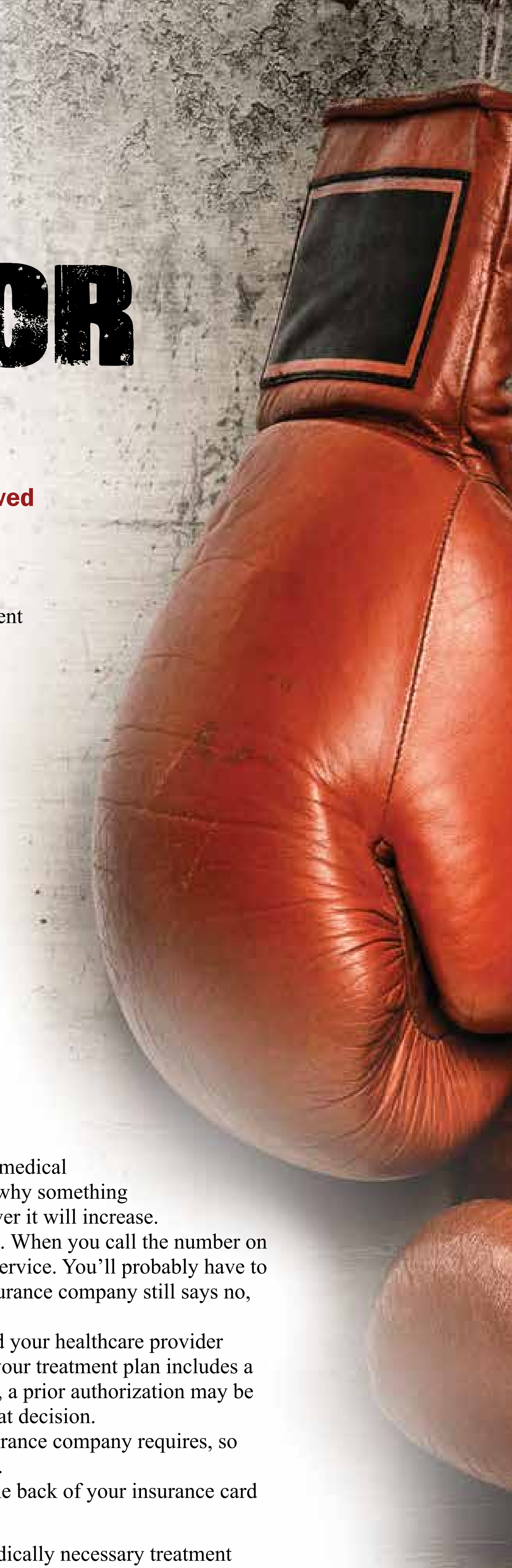

Your Health:

IT'S WORTH FIGHTING FOR

By Laurie Kelley

Q **I feel like I'm not really getting what I need from my healthcare coverage. What should I do if I've already received a denial of service or medication?**

A **Here are examples of denials that may happen:**

- Your health insurance company won't let you be seen at a hemophilia treatment center (HTC) for comprehensive care because the HTC isn't "in-network."
- You can't go to an HTC because you're in a health maintenance organization (HMO). Your managed care company doesn't have any physical therapists in-network experienced with bleeding disorders.
- Your HTC doctor prescribed a brand of factor replacement therapy, and your insurance company won't approve it.

What can you do about these denials?

Typically, people tell me they've just accepted the insurance company's decision and denial. But you need to be proactive. Did you or your healthcare provider ask the insurance company to reconsider? Did you file a complaint? You have a right to challenge the decision. You'll likely get help from your provider, and you may enlist the help of your local hemophilia organization. Consider asking for an appeal even if you have Medicaid. Sometimes, people with Medicaid feel they are getting "free" healthcare and don't want to rock the boat. No matter what type of healthcare coverage you have, you have the right to ask the company to reconsider.

Q **How about a few ideas to be me started on an appeal?**

A **Here are some ideas on getting what you need:**

- Insurance companies are in the business of providing care that leads to good medical outcomes for their members. If you and your healthcare providers can show why something is medically necessary, your chances of getting the insurance company to cover it will increase.
- If an HTC isn't in-network, ask the insurance company to make an exception. When you call the number on the back of your insurance card, be prepared to tell them why you need this service. You'll probably have to ask the HTC or provider to write a letter to the insurance company. If the insurance company still says no, you can file an appeal.
- If your insurance company doesn't agree with the treatment plan that you and your healthcare provider have agreed on, you may need a letter of medical necessity. For example, if your treatment plan includes a prescription for a different factor replacement therapy than you currently use, a prior authorization may be required. If the insurance company still doesn't approve it, you can appeal that decision.
- You'll need to follow the processes for complaints and appeals that your insurance company requires, so keep good records of phone calls and correspondence (emails, letters, forms).
- You can get the details on the company's process by calling the number on the back of your insurance card or going to the insurer's website.

Bottom line: If you and your healthcare team think that you're not getting medically necessary treatment approved, you've got to speak up!

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WFH Lead Research Points to Higher Global Hemophilia Prevalence

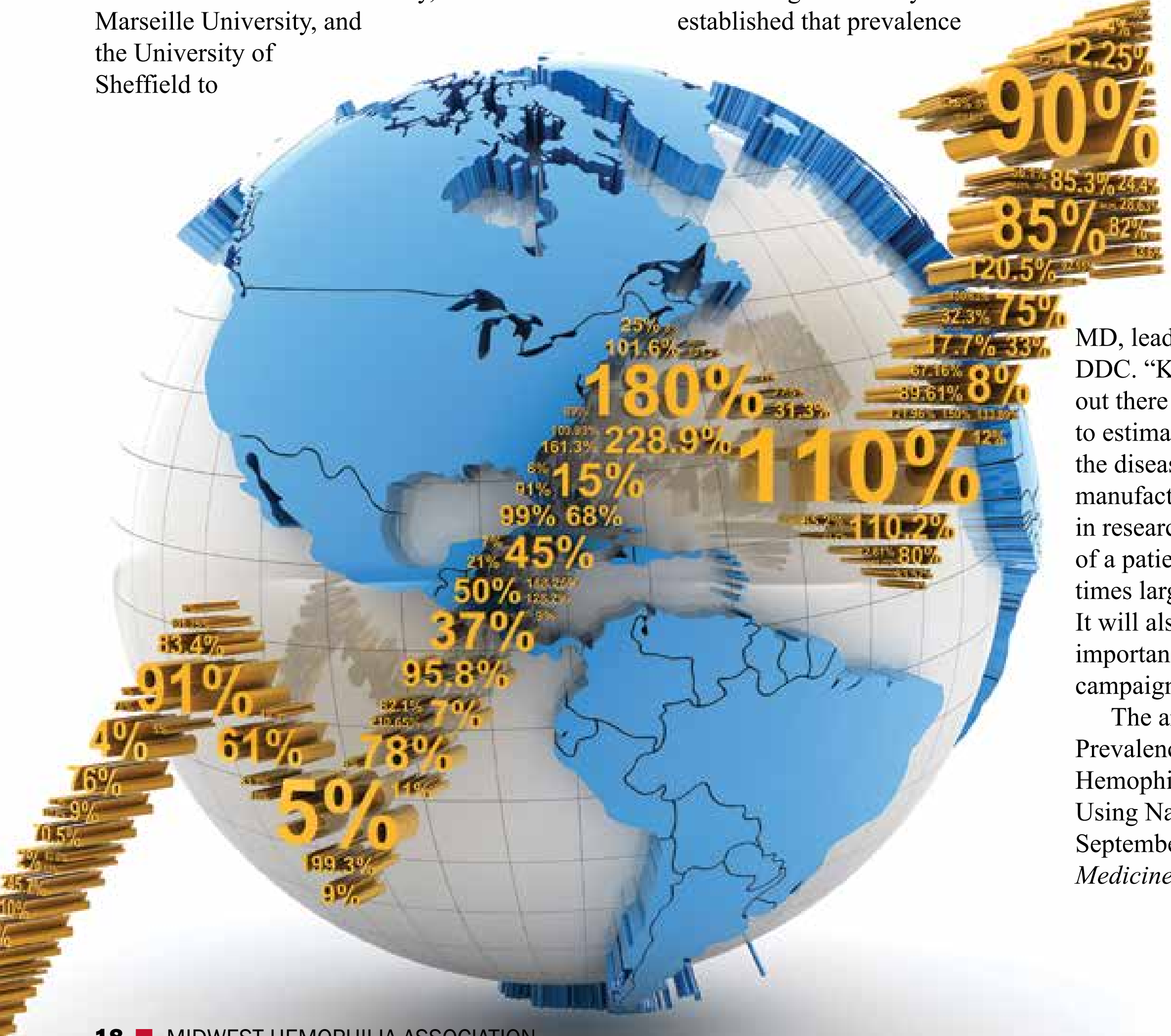
The World Federation of Hemophilia (WFH) recently announced the publication of a new study on the global prevalence of hemophilia, the results of which suggest a number that is significantly higher than the previous estimates. Findings from this eye-opening study were published in the *Annals of Internal Medicine*.

WFH recognized that having a clearer understanding of hemophilia prevalence will only enhance efforts to improve health care and quality of life for patients worldwide. They therefore put out a call to action that ultimately inspired researchers from McMaster University, North Carolina State University, Aix-Marseille University, and the University of Sheffield to conduct a meta-analysis of registry data in countries with comprehensive patient registries. These included Australia, Canada, France, Italy, New Zealand, and the United Kingdom. Investigators, working in concert with WFH's Data and Demographics Committee (DDC), uncovered a prevalence, per 100,000 males, of 17 for all severities of hemophilia A, 6 for severe hemophilia A, 4 for all severities of hemophilia B, and 1 for severe hemophilia B.

The study was unprecedented for also estimating hemophilia prevalence at birth, which is defined as the number of people born with hemophilia per 100,000 male births. Investigators' analysis established that prevalence at birth per 100,000 males is 25 for all severities of hemophilia A, 10 for severe hemophilia A, five for all severities of hemophilia B and two for severe hemophilia B. The study generated an overall global estimate of approximately 1,125,000 males with hemophilia, representing a dramatic increase when compared to the previous estimate of 400,000 worldwide. Further, 418,000 of these are estimated to have severe hemophilia, the majority of whom are undiagnosed.

"This paper is a milestone in our journey to providing care to hemophilia patients worldwide. Knowing how many patients are expected in each country given its population is an important measure of the efficiency of the health care system. Knowing how many patients should be there, and how many less are reported to national and international registries is a measure of the work left to be done," said Alfonso Iorio, MD, lead author and past-chair of the DDC. "Knowing how many patients are out there will enable health care systems to estimate the resources needed to treat the disease, and will enable drug manufacturers to increase the investment in research to match the demand of a patient population three times larger than previously thought. It will also serve to underline the importance of outreach and identification campaigns."

The article, "Establishing the Male Prevalence and Prevalence at Birth of Hemophilia: A Meta-Analytic Approach Using National Registries, appeared September 10, 2019 in *Annals of Internal Medicine*.



— Source: WFH press release dated September 10, 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

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Let's put science to work

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Keep track of your bleeds, infusions, and activity.

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The little app is getting bigger.

Talk to your doctor about HemMobile™— and which activities may be right for you.

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- Set reminders for resupply, appointments, etc
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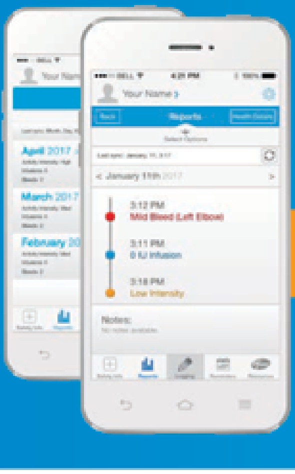

Download the app, pair your device, and start tracking

App Store | Google play

For iPhone† and Android™

Hemophilia can be difficult.
Tracking it shouldn't be.

HemMobile™ was designed to help you keep track of your bleeds, infusions, and factor supply.*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, 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 as well as your dosing regimen.

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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MOVING?
NEW ADDRESS?

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Midwest Hemophilia Association
PO Box 412866
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