

CHAPTER

Factors

SPRING 2021



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Connected



**Midwest
Hemophilia
Association**





Unite

for Bleeding Disorders

Saturday, October 16, 2021

@ Heritage Park – 16050 S Pflumm Road, Olathe, Kansas



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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 EXECUTIVE DIRECTOR



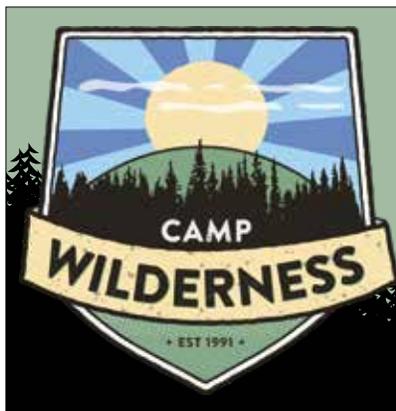
I think most of us thought it would be back to “business as usual” by this time. However, MHA continues to monitor and adapt to the current conditions in the community. Dates have been set for annual events and fundraisers. We will do our best to keep those dates and adjust whether they should be held in-person, online or as a hybrid.

Everyone is encouraged to attend all online programs since you can easily participate from your homes. In-person events this year may be hybrid programs--meaning a limited number of in-person attendees but live-streaming portions of the event so those who cannot travel but want to participate will have some access to do so.

If you have not been receiving emails or invitations from the chapter, please update your membership information on our website, www.midwesthemophilia.org. Otherwise, visit our website regularly for event details, information, and registration. You can also follow us on Facebook, Twitter, and/or Instagram.

I look forward to seeing you all however that may be!

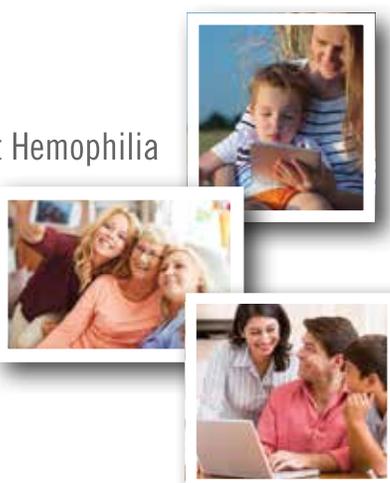
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QUICK NOTES

Attention Graduates!

We want to celebrate your accomplishments. If you are graduating from high school, trade school, or a college/university contact the MHA office to submit your profile information to be published in the Summer Chapter Factors Newsletter!

2021 F.A.B. to be a Hybrid Conference

We are currently planning for this year's F.A.B. Conference to be a hybrid event. Meaning, if you would like to attend sessions, but would be more comfortable participating online from the comfort of your own home you can still be part of the excitement! We have a great line-up of speakers and activities planned! You don't want to miss it.



The Only Constant is Change

As a certified senior citizen of the bleeding disorder community, I have seen a lot of change in my almost 70 years. We have gone from my brother having his tonsils out and almost bleeding to death in the 1950's to having our genes re-programmed to make factor. It's comparable to the Wright brothers making the first flight and we now have walked on the moon and are landing on Mars! I have to believe a permanent cure is in sight.

All this wonderful progress has not been without a price. I don't think I need to refresh anyone's memory about AIDS and Hep C. I dodged the AIDS bullet, but did contract Hep C. The first treatment for Hep C was Ribavirin and Interferon. I compared the treatment side effects to having a really severe case of the flu for six months. Many of my peers taking the treatment quit because they couldn't take the side effects. We now have

treatments that have almost zero side effects and seem to work like magic.

My involvement with the bleeding disorder community in various capacities has given me a front row seat for the evolution of various treatments. Young people growing up with a bleeding disorder today have multiple options, medicine delivery systems and even more exciting developments on the horizon. They are going to be able to experience a quality of life my generation never imagined. I have friends with frozen and deformed joints. You can usually spot most of us easily by our walk, sometimes affectionately referred to as the "swagger". The last I knew there are about 2,000 of us in the United States that are 65 and older. I think that number speaks for itself.

I can only speak for me, but I think we all have a God ordered duty to serve our fellow man. I hope when my generation is gone, we are remembered as the generation that made it happen for those that followed. I don't think any of us want pity, but a nice COVID inspired elbow bump would be nice... just make sure it's our good elbow!

— John Carleton

March is Bleeding Disorders Awareness Month

March is Bleeding Disorders Awareness Month! How are you sharing

FAB2021
Registration Open!

October 8-10, 2021 | Margaritaville
Osage Beach, MO

The "Females And Bleeding" Conference is a regional women's retreat brought to you by Gateway Hemophilia Association, Hemophilia of Iowa, Midwest Hemophilia Association, and the Nebraska Chapter of NHF

Sponsored by: **octapharma**
For the safe and optimal use of human proteins



your story? We would love to highlight community members who brought awareness about bleeding disorders in our next Chapter Factors Newsletter. Maybe you snapped a selfie during advocacy days, wrote a report for school, started your UNITE walk team, had an article written in the local newspaper, told a friend about your bleeding disorder, wore red all month! Whatever it was, contact the MHA office and tell us your story!

MHA Scholarships & More...

Deadlines for academic scholarships will be coming soon. Make sure to visit our website to download your applications.



2021 CALENDAR

To stay up-to-date on MHA events, please watch for email invites, check our chapter website, and follow us on social media. (Facebook, Twitter & Instagram)



April 1:
Teen Night
The BIG Secret - Online Escape Room

April 8:
Garden-Dodge Education Night
Importance of Community Connections

April 17:
World Hemophilia Day Celebration

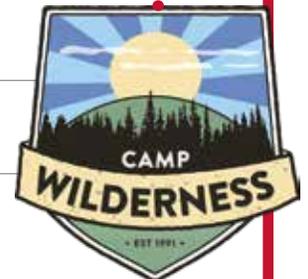
June 19:
Wichita Education Day
Never Have I Ever



July 17:
Springfield Education Day
Bleeding Disorder Trivia

August 2-6:
Camp Wilderness
*Lake Doniphan Conference & Event Center
 Excelsior Springs, MO*

August 26-28:
**NHF Bleeding Disorders
 Virtual Conference**



September 24:
23rd Annual MHA Golf Tournament

September 25-26:
29th Annual Family Education Weekend
@ Marriott KC, Overland Park, KS

October 8-10:
Females And Bleeding (F.A.B.) Conference
@ Margaritaville Lake Resort, Osage Beach, MO 65065

October 16:
UNITE for Bleeding Disorders Walk

October 21-24:
HFA Virtual Symposium



EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.



More than 20 years* of experience—the first recombinant treatment for individuals with hemophilia B



Dosing options to meet your needs—for once-weekly prophylaxis and on-demand use



Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix



The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called “inhibitors,” which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



BeneFix[®]

Coagulation Factor IX (Recombinant)

Room Temperature Storage

*BeneFix was approved February 11, 1997.

R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

Let's get together to talk about IXINITY®

Many families affected by a rare disease have compelling and uplifting stories of support to tell. I am honored to be part of the bleeding disorders community and to hear these stories firsthand.

—Craig Watkins, your resource for all things IXINITY



► Contact Craig at 816-550-7214 or craig.watkins@medexus.com

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Raising the Meadow Boys

Living life to the fullest despite living with chronic disorders

By Charity Meadows



I hope everyone made it through the crazy cold weather we had this past week. I enjoyed the pretty snow but I will not enjoy seeing the electric bill, am I right?? My kids enjoyed, what I like to call, hillbilly sledding, that is riding behind a 4 wheeler on top of a car hood. Who else grew up doing that? My husband and I own a salvage yard, so car hoods are plentiful. Of course, we made sure the boys were safe making sure they had factor and had plenty of space between the four wheeler and the sled. Sometimes, we make them wear their helmets but the snow was deep enough that if they fell off they had a soft landing. After all the fun in the snow we needed something warm to eat.

I found some soup recipes that were really good for those evenings we spent inside by the fire to keep warm. My favorite one is spicy corn and sausage chowder. I found this recipe on Instagram from The Gunny Sack. She has so many amazing recipes. I save every one of them so I can try them out, haha!

This recipe makes about 12 cups and takes only 30 minutes to make. The good thing about soups or chowders is that you can pretty much make them however you want them. Hot or mild spice, more garlic or less, tomatoes or none at all.

I hope you give this recipe a try the next time the weather gets cold and you need something to warm you up!

ABOUT THE AUTHOR: My name is Charity. I have been married 18 years to my wonderful hardworking husband Aaron and a mom to three handsome boys. My oldest son has a rare bleeding disorder, hemophilia B. My youngest has hemophilia B and type 1 diabetes. My middle child is just that, the classic middle child. Life is full of surprises, some good and some not so good. I hope this blog will encourage you that no matter what life throws at you, you can still live life to the fullest. This is our journey while living with chronic disorders. I hope to encourage you while raising awareness for Hemophilia B and Type 1 Diabetes. Hope you will stay awhile so we can encourage each other!!

SPICY CORN AND SAUSAGE CHOWDER

INGREDIENTS:

- 1 lb Italian sausage
- 4 cups chicken broth
- 3 cups potatoes
- 1 tbsp minced onion
- 1 tsp pepper
- 1 tsp crushed red pepper
(I left this out. You can make this as spicy as you want it or not.)
- 1 tsp parsley
- 1/2 tsp minced garlic
(or however much you want, I love garlic so I put more in)
- 16 oz Velveeta queso blanco cheese cubed
(I could not find this, but I did find some queso dip in the refrigerated cheese section at Walmart and thought it worked great)
- 15 oz can of corn
- 2 cups half and half
- 1/2 cup rotel or, I think I put a can in.

DIRECTIONS:

Let's put it all together! Brown and drain the sausage and set aside.

Put the chicken broth, diced potatoes, minced onion, pepper, garlic, crushed red pepper, and parsley in a large stockpot. Bring to a boil over medium heat. Reduce heat and simmer for 15 minutes or until the potatoes are tender. Add the cooked sausage, half and half queso, drained corn and drained tomatoes. cook for 5 minutes, until the cheese is melted and chowder is heated through. Serve up with some cornbread or bread.





In the times we are currently living in, it is important to stay connected with those you know. MHA is pleased to continue to offer our chapter family opportunities to connect with each other by providing monthly virtual Community Outreach Programs (vCOP) on our MHA Zoom platform. This is a secure and safe online medium easily used by even the least experienced 'techie'. If you have not participated in one of these C.O.P.s you are definitely missing out!

If you are not receiving email invites to attend these events or others, you most likely need to update your contact information with us. You can do that by contacting the MHA office or going to our website, www.midwesthemophilia.org and registering as a member!

Check out a few photos of online events we have offered. We hope to see you at the next one! (If you need assistance figuring out how to use Zoom, feel free to contact the office and someone will walk you through the process!)



Love and laughter filled the air during this virtual education and paint night.



**Tacos anyone?
Families gathered
around their computers to
learn how to make 'gourmet'
sesame beef tacos!**



**It was an EGG-cellent
night in Kevin's Kitchen
learning how to make
deviled eggs and listening
about healthy eating habits.**



**Camp Wilderness Razzle-Dazzle
Goose Chase Game Night: Camp
volunteers play an online scavenger
hunt game, Goose Chase, to collect
points for their "cabin".**





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LET'S GO

Keep Your Lower Extremity Joints

MOVING!

By Michael Zolotnitsky, PT, DPT

The pandemic impacted everyone's life in 2020, making it especially hard to stay healthy. While many of us began exercising from home, some of us have completely stopped exercising because of the increased stress of working from home, managing our children's school schedules, gyms closing, expensive home exercise equipment, or just being out of routine. This isn't good for anyone, but if you have a bleeding disorder, lack of exercise can cause major setbacks, including joint stiffening, that put you at greater risk of joint bleeds and more joint damage.

As a physical therapist with severe hemophilia, I'm going to focus on eight imperative workouts to perform daily without any equipment at all. And I'll explain why these are important to maintain strength and reduce areas of common joint damage!

1. Sit to Stand: Sit in a chair, cross your arms, keep feet shoulder-width apart, toes pointed forward, and stand up. Slowly lower yourself into the chair, repeating 9 more times for a total of 10. If this is challenging, use your arms for support until your legs build strength. If this is easy, find a lower surface.

PURPOSE: Build strength through the quads and glutes to reduce difficulty with walking and stair negotiation, while reducing pressure on the knee and hip joints.

2. Glute Bridges: Lie on your back, making sure your spine is neutral. Bend both knees, keeping your feet on the floor. With your knees slightly apart, push through your heels to raise the hips up. If this is challenging, use your arms to help push your body up. If this is easy, progress to perform one leg at a time.

PURPOSE: Build strength through the glutes and the hamstrings. Also great for core activation and balance if performing with one leg. Building up sufficient glute and hamstring strength will also reduce pressure on the knee and hip joints.

3. Standing Hip Abduction: Stand facing a wall, with hands on the wall, knees shoulder-width apart. Start with one leg. Slowly bring it out to the side with toes pointing forward, and then return. Begin with 10–12 repetitions (reps) and progress to 15–20, making sure your body is not

rocking sideways. If this is easy, progress to doing the reps without holding onto the wall. While performing this on the right side, the left side is focused on stabilizing, so both hips will feel the workout!

PURPOSE: Build strength in the *gluteus medius*, which will keep you upright when walking and improve overall balance to reduce your risk of falling.

4. Standing Hip Extension: Stand facing a wall, with hands on the wall, knees shoulder-width apart. Start with one leg, and slowly extend the leg back, with toes pointing forward. Make sure the lower back is not arching backward or forward; squeeze the glute to engage proper activation. Begin with 10–12 repetitions (reps) and progress to 15–20, making sure your body is not rocking sideways. If this is easy, progress to not holding onto the wall.

PURPOSE: Build endurance to reduce difficulty in activities requiring prolonged periods, such as hiking or taking long walks. Improving glute strength and performing standing extension-based exercise is important because we are often in the flexed posture throughout the day.

5. Penguins: Stand with your toes pointing forward, and waddle side to side, standing in place. You'll feel this in the sides of both hips. Begin for 10–20 seconds with feet 1 to 2 inches apart, and progress to 30–60 seconds with feet 3 to 5 inches apart.

PURPOSE: Build further *gluteus medius* strength and improve balance. While you balance on the one lower extremity, the other is working. Balance training has been shown to reduce pain in the ankle and knee, and reduce effects of osteoarthritis.

6. Heel Raises: Stand facing a wall, with hands on the wall, toes pointed forward. Slowly raise your body up on tiptoes. Progress to not holding onto the wall, and further progress by standing on toes using both feet going up, and then lowering down on one. Start with 10–15 reps, and progress to 20–30 reps.

PURPOSE: Build strength through the calves, to improve strength during walking. Ankle bleeds are common, but ankle muscles are not commonly exercised. Having strong ankles will reduce strain that moves up through the knee, hip, and lower back.

7. Hip Flexor Stretch: Kneel on one knee, with the other at a 90-degree angle in front of you. Maintain upright posture, and keep your sternum/chest bone pointing upward. Slowly lean forward and feel the stretch through the groin. Begin by holding 15–20 seconds if you're under age 65, and holding 30–60 seconds if you're over 65, to help stretch the collagen. Progress by engaging the glutes to feel an increased stretch through the iliopsoas.

PURPOSE: Reduce strain on the quad and low back by improving mobility and flexibility of the hip flexor. Since most people are in a flexed posture and seated position for long periods, the iliopsoas tends to get super tight and is an area of increased muscle bleeds. Maintaining good range of motion will reduce the chance of target joints.

8. Hamstring Stretch: In a seated position, have your legs apart, and slowly lean toward one ankle. Begin by holding 15–20 seconds if you're under age 65, and 30–60 seconds if you're over 65 to stretch the muscle. Progress by reaching farther to improve the stretch.

PURPOSE: Reduce strain on the low back and knee joints by improving the mobility and flexibility of the hamstrings. If you spend a lot of time in a flexed posture and seated position, the hamstrings tend to get super tight. Maintaining good range of motion will reduce the chance of developing target joints.

A pandemic can make working out a challenge. These eight simple exercises focus on mobility, balance, and stability, and target all the major muscle groups. They can be performed at home without any equipment. I highly recommend performing these exercises daily, and after six to eight weeks, you'll see a major improvement. Exercise is vital if you have a bleeding disorder. The time to start is NOW!

Michael Zolotnitsky, PT, DPT, is director of neurological rehabilitation at New Jersey Spine and Wellness in Old Bridge, New Jersey. He also has severe hemophilia A. He can be reached at 732-952-2292 and michael.zolotnitsky@spineandwellness.com

Brittany Slossberg

Relationship builder

About Brittany

Brittany is a Hemophilia Community Liaison who has a passion for creating long-lasting relationships with others. She has built a strong comradery with many patients in the Colorado community.

Connect with Brittany

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(561) 289-3275



Hemophilia Community Liaison

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HemDifferently

Exploring the science behind gene
therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at HemDifferently.com

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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ADVOCACY

In preparation for both NHF Washington Days and State Advocacy Days, MHA and GHA collaborated to provide an online program, “Understanding Accumulator Adjusters”, presented by Kollet Koulianos, NHF Director of Policy and Advocacy to MHA and GHA’s community membership in February. While there is other state legislation our chapter has been monitoring (Step Therapy in Kansas and Medicaid Expansion in Missouri), our main focus this year at the state level is with insurance accumulator adjusters.

Accumulator Adjuster Programs (AAPs), sometimes called co-pay adjusters, are “a new cost-containment tactic” that Pharmacy Benefit Managers provide. These health insurance programs affect people who use drug copay cards or copay assistance programs by not counting the payment that these cards/programs assist with towards the deductible or out-of-pocket cost set by the insurance company. This is a major concern for our bleeding disorders community.

MHA is also looking for community advocates and

POLICY PRIORITY:

Make sure that all copays count!

Many in the bleeding disorders community rely on patient copay assistance programs to help defray the out-of-pocket (OOP) cost of their prescription drugs. Unfortunately, health insurers increasingly are refusing to credit copay assistance toward patients’ deductibles and OOP maximums.

BACKGROUND:

Accumulator adjusters are a new cost-containment tactic that have rapidly expanded to the point where they now appear in up to 80% of commercial health plans. Plans frequently have discretion to spring accumulators on consumers at any time and conceal their existence in plan documents that are hundreds of pages long, disguising them under confusing names like “out-of-pocket protection programs” or “specialty copay solutions.”

IMPACT:

Accumulators create significant confusion, financial risk, and barriers to care for consumers. Patients find that they can’t afford to remain on their medications: they then have to weigh discontinuing treatment, or turning to emergency rooms for care. Both options lead to bad health outcomes AND higher health care spending overall. Patients exposed to sky-high, year-after-year OOP costs face threats to their financial security as well as their physical wellbeing.

WHAT IS BEING DONE TO PREVENT ACCUMULATOR ADJUSTERS:

To date, five states and one territory (Virginia, West Virginia, Arizona, Illinois, Georgia, and Puerto Rico) have passed laws prohibiting or limiting the use of accumulator adjusters for all individual and small group plans.

HFA’s POSITION:

All copays count! Protect patients from high out-of-pocket costs by requiring health plans to credit all payments made by or on behalf of patients toward patient deductibles and out-of-pocket maximums. Copayment accumulator adjusters endanger patient health and well-being.

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FOCUS

constituents living in Kansas to participate in future advocacy days. If you are interested in helping develop our Kansas Advocacy Day committee, please contact the MHA office at 816-479-5900 or info@midwesthemophilia.org.

The information on this spread has been provided by Hemophilia Federation of America (HFA) help members to better understand the impact of the AAPs and what can be done to prevent accumulator adjusters. Additional information can be found on its website www.hemophiliafed.org



• WHAT IS COPAY ASSISTANCE?

Copay assistance (sometimes called “copay cards” or “coupons”) is money that helps patients afford out-of-pocket costs for their medications. Patients with chronic conditions such as bleeding disorders need specialty medications to manage their disease. Copay assistance is often the only way that they can afford the out-of-pocket costs for their life-saving medications.

• DOES COPAY ASSISTANCE INCREASE USE OF EXPENSIVE MEDICATIONS?

No. For conditions such as bleeding disorders, no generic and no low-cost alternatives exist. And health insurers still have control of what treatments patients can access, using their traditional tools of formulary design, prior authorization, etc. Patients must still gain approval from the insurer to gain access to the medication at issue.

• WHAT HAPPENS WHEN COPAY ASSISTANCE IS NOT ALLOWED TO COUNT?

When an insurer applies an accumulator, the insurer collects double (or more) the amount of a patient’s required costsharing: once from the copay assistance program and then, when the assistance dollars are depleted, the full amount of the cost-sharing (again) from the patient themselves. This double-dipping represents a best-case scenario: it assumes that the patient can afford to pay that cost-sharing and access their medication. All too often, patients abandon their prescription instead, or are forced to seek treatment in a higher cost setting such as an emergency room.

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Missouri and Kansas hemophilia community.

Danielle Kempker
CoRe Manager for Missouri & Kansas



Let's connect.

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Facebook: @HemophiliaCoRes



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Sunday 4:07 pm
Enjoying a game of checkers with his wife
Alan, living with hemophilia A with inhibitors

Not an actual patient

WE'RE IN THIS TOGETHER.

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com



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HELPFUL NUMBERS

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HEMOPHILIA CENTER**
1-816-302-6869 • 1-800-236-1713

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Dr. Shannon Carpenter • Dr. Michael Silvey
Dr. Lauren Amos

ADULT PHYSICIANS:

Dr. William Jennings • Dr. Jill Moormeier • Dr. Anuj Shrestha

**UNIVERSITY OF MISSOURI
HOSPITAL AND CLINICS
HEMOPHILIA TREATMENT CENTER**
1-573-882-9355

NATIONAL HEMOPHILIA FOUNDATION (NHF)
1-800-42-HANDI • www.hemophilia.org

HEMOPHILIA FEDERATION OF AMERICA (HFA)
202-675-6984 • www.hemophiliafed.org



Amos



Carpenter



Jennings



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Save the Date!

**23rd Annual
MHA Golf Tournament**

SEPTEMBER 24, 2021

WINTERSTONE GOLF COURSE

7am Check-in / 8am Tee Time



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

1471 W. South St, Suite F
Ozark, MO 65721

We're Listening



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team