

# BIOMATRIX

## NEWS



**DEDICATED  
TO MAKING  
A DIFFERENCE**

**WINTER 2021  
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**“ With girth and laughter,  
let old wrinkles come. ”**

— William Shakespeare

## ABOUT BIOMATRIX

BioMatrix Specialty Pharmacy is removing burden, improving health, and making life easier for patients with chronic, difficult to treat conditions.

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving

quality of life for patients and producing positive outcomes along the healthcare continuum.

Our services include the clinical monitoring, tracking, and management tools required by today's healthcare stakeholders while providing individualized patient support leading to better health outcomes.

## MISSION + VISION

The **MISSION** of BioMatrix is to improve outcomes through individualized specialty pharmacy services empowering patients to live each day to its fullest potential.

Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

**INTEGRITY** – Our professionalism, strength, and stability come from our resolve to operate honestly, morally, and with a higher purpose to meet and exceed the expectations of all.

**DEDICATION** – Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close family feel.

Our **VISION** is to set the standard for exceptional care, maximizing the health and satisfaction for each patient served.

**COMPASSION** – We are sensitive to each individual's unique situation. Our ability to listen, empathize, and support those we work with distinguishes our business practice.

**ENRICHMENT** – We understand that in order to perform at our best, we must always seek to learn and grow while using our knowledge to assist and empower others.

**ENTHUSIASM** – Our confidence in the services we provide is illustrated by the energy, drive, and passion we exhibit in all we do.

## FINE PRINT

**Editor-in-Chief: Maria Santucci Vetter**

**Editors: Susan Moore and Justin Lindhorst**

The purpose of BIOMATRIX NEWS is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, or others associated with BIOMATRIX NEWS or that of BioMatrix.

Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

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## A NOTE FROM THE EDITOR

Dear Readers:

2020 is behind us! It was a challenging year for many so let's all take a deep breath and welcome the New Year! Though life will not instantly be "normal," hopefully, 2021 will show a strong start in that direction. I, for one, can't wait to be out in the community attending educational conferences and symposiums. Online options are great, but there's nothing like seeing old friends and meeting new families in person.

Being adaptive, many of us have learned to juggle working from home, have figured out how to navigate Zoom meetings, and have tackled relearning and explaining middle school math. It's been one of the few times I've been glad my kids are grown.

As a community, we've tackled other difficult times and we always manage to get through them with positive, resilient attitudes. I love "our" people! Despite the challenges of 2020, there were still blessings to be found. Many

people still experienced the usual happy events, birthday milestones, school graduations, weddings, the birth of babies, and the perfecting of baking skills!

In closing, our cover features a few of the fantastic photos that can be found in our BioMatrix *2021 Living a Spectacular Life* calendar. If you would like one of our free, coveted calendars, please contact your local Regional Care Coordinator or drop me a line directly. We are happy to mail one out to you!

Better days are definitely ahead – let's continue moving forward!

Enjoy your winter!

Maria Santucci Vetter  
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# New Year, New Plan, Major Headache?

## How to Avoid Access to Care Issues in the New Year

BY: JUSTIN LINDHORST

**For those living with a chronic health condition, ringing in the New Year can mean a ringing headache when it comes time to access specialty medication. That's because January marks not only the new calendar year but also the start of a new plan year for your health insurance coverage.**

Whether you've selected a new plan or maintained coverage on an existing one, the New Year marks a reset button for deductibles, co-insurance, and other patient financial responsibilities. It's also the time when any changes your insurance plan has made to coverage goes into effect. This can mean new prior authorization requests, requirements to demonstrate medical necessity, or being directed to a new service provider. Taken together, these can contribute to access issues leaving patients who need specialty drugs in a predicament.

This article outlines how specialty pharmacies like BioMatrix can help patients avoid access to care issues, provides tips and best practices you can implement, and includes links to helpful resources.



### SPECIALTY PHARMACY SUPPORT

Anyone who has a chronic health condition can identify a time they've had to spend a significant amount of time on the phone with their health insurance plan. Unfortunately, patients share it's not entirely uncommon to be told one thing by one customer service representative, only to be told something entirely different by another.

Specialty pharmacies can help break down barriers to care and cut through red tape by conducting a thorough benefits investigation, facilitating access to financial support programs, and working with your insurance plan and medical team to provide support for prior authorizations and appeals.

Specialty pharmacies such as BioMatrix employ staff who are very well versed in promptly identifying and resolving coverage issues specific to your health condition. The first tool at their disposal is conducting a comprehensive benefits investigation. The benefits investigation provides a detailed outline of coverage specific to your therapy, including whether it is covered under the medical or pharmacy benefit, whether the medication requires prior authorization, your financial responsibility, and what specialty pharmacy service providers are available under the plan.

After the benefits investigation is complete, the specialty pharmacy can refer you to available and appropriate

# NEW YEAR'S RESOLUTION

Be proactive

Work with  
HTC Social  
Worker

Keep  
detailed  
records

Document  
medical  
necessity

Check for  
copay  
accumulators

Understand  
the appeal  
process

Organize  
paperwork

patient assistance programs to reduce financial barriers to care. They can also work together with your medical provider and health plan to obtain timely prior authorization for service and assist when and if an appeal is necessary.

Asking your provider to send a referral to BioMatrix or another reputable specialty pharmacy is a good first step in avoiding coverage issues.

## MAINTAINING ACCESS TO CARE TIPS AND BEST PRACTICES FOR 2021

There are also steps you can personally take to avoid access issues. Following the guidelines below can go a long way in resolving potential barriers.

### BE PROACTIVE:

Don't wait until you are critically low on medication to place your first order in the New Year. Placing your order in a timely manner will give your medical provider and specialty pharmacy enough time to resolve any issues before it potentially disrupts your care.



### WORK WITH THE HTC SOCIAL WORKER

If you are experiencing or anticipate coverage issues, it's important to engage your Hemophilia Treatment Center. According to the National Hemophilia Foundation, HTC social workers assist with issues of daily living, including insurance.<sup>1</sup> From identifying coverage options to overcoming coverage challenges, your HTC social worker is an important member of your advocacy team. If your HTC does not have a social worker, reach out to your nurse or hematologist.

### KEEP DETAILED RECORDS:

When you need to contact your insurance provider regarding any issue or concern, it's very important to document every call. Keep notes on the following: date



and time of the call, the reason for the call, name of the person you spoke with, the result of the call, reference number, and any impact on your health resulting from the issue/call.

### DOCUMENT MEDICAL NECESSITY:

Work with your medical provider to document the medical necessity of your treatment. Having robust documentation on file can speed the resolution of issues related to prior authorization, denials, step therapy, or appeals. Ask your provider to write a letter on official letterhead identifying your diagnosis, the therapy you have been prescribed and why, any previously failed treatments, and the consequences of not having access to your prescribed therapy.

Include medical records, clinical evaluations, or other supplemental documentation supporting your diagnosis/treatment. Keep a copy for your personal records, and request a copy be kept on file with your specialty pharmacy.

### CHECK FOR COPAY ACCUMULATORS:

If you are using a manufacturer or other third-party copay assistance program, determine if your plan is using a copay accumulator. Verify with your specialty pharmacy whether payments are being received from the copay assistance program you are enrolled in.

*continued on page 9...*



Bleed Have to cancel  
Late for school  
When will this bleed end?  
Another bleed  
Time Visit to ER  
Frustration Bleed



For the treatment of bleeding episodes in people\* with hemophilia A or B with inhibitors<sup>1</sup>

## HE'S READY TO MOVE ON

Give your patients rapid, predictable, and reliable bleed control with **SEVENFACT 225<sup>†2</sup>**



### Rapid effect: 3 hour

At 3 hours, 84% of mild/moderate bleeding episodes were controlled with a single dose<sup>2</sup>



### Predictable<sup>‡</sup> response: 84%

At 9 hours, 84% of mild/moderate bleeding episodes treated achieved bleed control after one dose<sup>2</sup>



### Reliable control: 99.5%

At 24 hours, 99.5% of mild/moderate bleeding episodes were resolved<sup>2</sup>



### Convenient home use: 98%

98% of bleeding episodes were treated at home<sup>1</sup>

<sup>†</sup> 225 µg/kg initial dosing regimen in the clinical trial.

<sup>‡</sup> As seen in the clinical trial.

## Summary of Selected Safety information

### **WARNING: THROMBOSIS**

- **Serious arterial and venous thrombotic events may occur following administration of SEVENFACT.**
- **Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive SEVENFACT.**
- **Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis.**

### **Contraindications**

SEVENFACT is contraindicated in patients with known allergy to rabbits or rabbit protein, or severe hypersensitivity reaction to SEVENFACT or any of its components.

### **Warnings and Precautions**

There is limited information about the safety of SEVENFACT in patients with a history of arterial or venous thromboembolic disease, because such patients were excluded from SEVENFACT trials. Serious arterial and venous thrombotic reactions can occur with SEVENFACT and have been reported in clinical trials and postmarketing surveillance with a similar class of products.

The following patients may have an increased risk of thromboembolic events with use of SEVENFACT:

- History of concomitant treatment with aPCC/PCC (activated or non-activated prothrombin complex) or other hemostatic agents.
- History of atherosclerotic disease, coronary artery disease, cerebrovascular disease, crush injury, septicemia, or thromboembolism.

Hypersensitivity reactions, including anaphylaxis, are possible with SEVENFACT. Should symptoms occur, patients should discontinue SEVENFACT and seek appropriate medical intervention. Patients with known hypersensitivity to casein may be at higher risk of hypersensitivity reaction.

### **\*Indications and Usage**

SEVENFACT [coagulation factor VIIa (recombinant)-jncw] is indicated for the treatment and control of bleeding episodes occurring in adults and adolescents (12 years of age and older) with hemophilia A or B with inhibitors.

SEVENFACT is not indicated for the treatment of patients with congenital Factor VII deficiency.

### **Adverse Reactions**

The most common adverse reactions reported in clinical trials for SEVENFACT were headache, dizziness, infusion-site discomfort, infusion-site hematoma, infusion-related reaction, and fever.

### **Drug Interactions**

Clinical experience with pharmacologic use of FVIIa-containing products indicates an elevated risk of serious thrombotic events when used simultaneously with activated prothrombin complex concentrates.

**Please see next page for Brief Summary of Prescribing Information**



## Brief Summary of Prescribing Information for SEVENFACT [coagulation factor VIIa (recombinant)-jncw], for Intravenous Use

### INDICATIONS AND USAGE

SEVENFACT® [coagulation factor VIIa (recombinant)-jncw] is indicated for the treatment and control of bleeding episodes occurring in adults and adolescents (12 years of age and older) with hemophilia A or B with inhibitors.

Limitation of Use: SEVENFACT is not indicated for the treatment of patients with congenital Factor VII deficiency.

#### WARNING: THROMBOSIS

- **Serious arterial and venous thrombotic events may occur following administration of SEVENFACT.**
- **Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive SEVENFACT.**
- **Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis.**

### CONTRAINDICATIONS

SEVENFACT is contraindicated in

- known allergy to rabbits or rabbit proteins. Exposure to SEVENFACT in these patients can result in severe hypersensitivity reaction.
- patients with severe hypersensitivity reaction to SEVENFACT or any of its components. Exposure to SEVENFACT in these patients can result in severe hypersensitivity reaction.

### WARNINGS AND PRECAUTIONS

#### Thrombosis

- There is limited information about the safety of SEVENFACT in patients with a history of arterial or venous thromboembolic disease, because such patients were excluded from SEVENFACT trials. Serious arterial and venous thrombotic reactions can occur with SEVENFACT. Such reactions have been reported in clinical trials and post-marketing surveillance with a similar class of products. Neither arterial nor venous thrombotic events have been reported in SEVENFACT clinical trials.
- The following patients may have increased risk of thromboembolic events with use of SEVENFACT:
  - History of congenital or acquired hemophilia receiving concomitant treatment with aPCC/PCC (activated or non-activated prothrombin complex) or other hemostatic agents
  - History of atherosclerotic disease, coronary artery disease, cerebrovascular disease, crush injury, septicemia, or thromboembolism.
- Monitor patients who receive SEVENFACT for the development of signs and symptoms of activation of the coagulation system or thrombosis. When there is laboratory confirmation of intravascular coagulation or presence of clinical thrombosis, reduce the dose of SEVENFACT or stop treatment, depending on the patient's condition.

#### Hypersensitivity Reactions

- No hypersensitivity reactions have been reported in SEVENFACT trials; however, hypersensitivity reactions, including anaphylaxis, can occur with SEVENFACT. Symptoms may include hives, itching, rash, difficulty breathing, swelling around the mouth and throat, tightness of the chest, wheezing, dizziness or fainting, and low blood pressure. In the event of hypersensitivity reactions, patients should discontinue treatment and seek immediate medical attention.
- Patients with known IgE-based hypersensitivity to casein may be at higher risk of hypersensitivity reactions. Should signs or symptoms of hypersensitivity occur, treatment should be discontinued. Subsequent treatment with SEVENFACT should be based on a thorough assessment of the risks and benefits.

#### Neutralizing Antibodies

- In the studies performed, no patients tested positive for neutralizing antibodies. Nevertheless, neutralizing antibodies may occur with the use of SEVENFACT. If treatment with SEVENFACT does not result in adequate hemostasis, then suspect development of neutralizing antibody as the possible cause and perform testing as clinically indicated.
- Neutralizing antibodies to other Factor VIIa-containing products have been observed in congenital Factor VII-deficient patients. SEVENFACT has not been studied in this patient population. [See *Limitation of use statement under Indications and Usage (1)*].

#### Laboratory Tests

Laboratory coagulation parameters (PT/INR, aPTT, FVII:C) do not correlate with clinical response to SEVENFACT treatment.

### ADVERSE REACTIONS

The most common adverse reactions (incidence  $\geq 1\%$ ) reported in clinical trials for SEVENFACT were headache, dizziness, infusion-site discomfort, infusion-site hematoma, infusion-related reaction, and fever.

#### Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice.

In two studies of SEVENFACT in patients with Hemophilia A or B with or without inhibitors, 42 subjects (27 subjects in Study 1 and 15 subjects in Study 2) have been exposed to SEVENFACT.

Study 1: The safety of SEVENFACT has been evaluated in a safety and efficacy study of 27 subjects with Hemophilia A or B with inhibitors, which included treatment of 468 bleeding episodes. As described in Table 2, a total of seven adverse reactions were observed in two subjects (7.4%) treated with SEVENFACT. One episode of fever occurred in a 12-year-old subject, lasted two days, and was managed symptomatically.

Study 2: In a study with 15 subjects evaluating the safety and pharmacokinetics of three escalating doses of SEVENFACT (25 mcg/kg, 75 mcg/kg and 225 mcg/kg), a total of three (20%) subjects experienced four adverse reactions (Table 1).

One subject developed an infusion reaction immediately following the infusion of the first dose of 75 mcg/kg; the reaction lasted 45 minutes. Signs and symptoms included flushing, chest tightness, shakiness, transient tachycardia, and mild hypotension. Symptoms resolved without any intervention and did not recur with subsequent administration at 225 mcg/kg dose.

Adverse reactions reported in the two clinical studies are shown in Table 1.

Table 1 Adverse Reactions Occurring in the Two Clinical Studies

Preferred Terms	Number of Adverse Reactions in Study 2 (N=15)	Number of Adverse Reactions in Study 1 (N=27)
Infusion-site discomfort	–	4
Infusion-site hematoma	–	2
Dizziness	2	–
Headache	1	–
Body temperature increased	–	1
Infusion-related reaction	1	–

#### Immunogenicity

In Study 1, two out of 27 subjects had a positive screening assay for anti-SEVENFACT antibody at baseline, prior to exposure to SEVENFACT, and at follow-up visits. One of these two subjects had a transient SEVENFACT antibody with an additional confirmatory test for anti-SEVENFACT antibody, which was confirmed as non-neutralizing. In Study 2, five of 15 subjects tested positive for anti-SEVENFACT antibody using a screening assay. The confirmatory assay was negative for all subjects at all time points.

No subject developed anti-rabbit milk protein antibodies during treatment with SEVENFACT. As with all therapeutic proteins, there is potential for immunogenicity. The detection of antibodies is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors, including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to SEVENFACT with the incidence of antibodies to other products may be misleading.

#### DRUG INTERACTIONS

Clinical experience with pharmacologic use of FVIIa-containing products indicates an elevated risk of serious thrombotic events when used simultaneously with activated prothrombin complex concentrates.

#### USE IN SPECIFIC POPULATIONS

##### Pregnancy

###### Risk Summary

There are no adequate and well-controlled studies using SEVENFACT in pregnant women to determine whether there is a drug-associated risk. Animal studies evaluating the embryo-fetal teratogenic potential of SEVENFACT have not been conducted. It is unknown whether SEVENFACT can cause fetal harm when administered to a pregnant woman or can affect fertility. In the U.S. general population, the estimated background risks of major birth defect and miscarriage in clinically recognized pregnancies are 2-4% and 15-20%, respectively.

##### Lactation

###### Risk Summary

There is no information regarding the presence of SEVENFACT in human milk, the effect on the breastfed infant, and the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for SEVENFACT and any potential adverse effects on the breastfed infant from SEVENFACT or from the underlying maternal condition.

##### Females and Males of Reproductive Potential

###### Risk Summary

In Study 1, male patients cautioned to avoid sexual activity without condoms received SEVENFACT for the treatment of bleeding episodes. No pregnancies from sexual partners were reported. The relative benefits of SEVENFACT should be weighed against any potential risk arising from exposure in sexually active patients.

All clinical studies of SEVENFACT were performed on males, as males are predominantly affected with the congenital form of hemophilia. No adverse effects on the mating index, fertility, or conception rate were observed following administration of SEVENFACT at dose levels up to 13-fold higher than the highest recommended human dose in healthy male rats prior to and during cohabitation with healthy untreated female rats [See *Carcinogenesis, Mutagenesis, Impairment of Fertility (13.1)*].

##### Pediatric Use

Limited clinical data for SEVENFACT in the pediatric population were collected in an adult and adolescent study (Study 1). A total of 5 subjects aged  $\geq 12$  to  $<18$  years of age (range 13-17 years) were dosed with SEVENFACT. These 5 subjects were treated for a total of 79 bleeding episodes (all mild or moderate) that occurred while subjects were still under 18 years of age. Hemostatic efficacy in this subgroup (n=5) was comparable to efficacy observed in the overall population [See *Clinical Studies (14)*].

##### Geriatric Use

Safety and effectiveness of SEVENFACT in patients  $>65$  years of age have not been evaluated in clinical trials. The presence of age-related comorbidities and the attendant risks associated with thrombotic and thromboembolic events should be considered when administering SEVENFACT to patients older than 50 years of age.

#### OVERDOSAGE

There have been no reports of overdosage with SEVENFACT. Doses greater than 900 mcg/kg/day have not been studied. Doses greater than 900 mcg/kg per 24 hours may be associated with an increased risk of thromboembolic events.

**To report SUSPECTED ADVERSE REACTIONS or product complaints, contact HEMA Biologics at 1-855-718-4362. You may also report SUSPECTED ADVERSE REACTIONS to the FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch).**

#### References:

1. SEVENFACT [Prescribing Information]. HEMA Biologics; 2020.
2. Data on File. HEMA Biologics.

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**HEMA**  
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Once you've verified payments are being made, check your Explanation of Benefits (EOB). If the payments from your assistance program are not being applied to your out-of-pocket costs, your plan may be using an accumulator program.

### **UNDERSTAND THE APPEAL PROCESS:**

Every plan's process for an appeal varies. Check with your insurance provider to determine their specific appeal process. Don't hesitate to involve your medical provider and specialty pharmacy for additional assistance.

Understand the denial of the claim by investigating the explanation of benefits statement (EOB). There is often a code noted on the EOB if there is a denial of coverage or a letter with codes and a key code to decipher what the denial was based upon. Identifying the code will allow you to see if it was a true denial or a basic miscoding by the provider or insurance.



Keep all documentation including referrals, doctor's notes, medical history, medicines or prescriptions, and notes from all contact with providers or insurance regarding the claim. The burden of proof is in your hands.

### **ORGANIZE YOUR PAPERWORK:**

If you have the aforementioned documents, you might also need to write a letter to the insurance company (written appeal). Keep documentation of your claim number, insurance information, provider/services information readily available. Request a reference number and employee name for every phone call to your insurance plan.

Be cognizant of the appeal timeline (30/60/90 days in many cases). Be sure to file all paperwork and make calls within the timeline allowed. If your appeal is denied a second time you may be able to file another appeal. Some aspects of the ACA mandate states allow an external review process for denied claims.



Follow up on every call, text, email, and mail document you submit. Be sure it has a record of receipt.

The first of the year can be challenging for patients who require specialty medication. Avoid any potential disruptions in care by leveraging every resource at your disposal. Work with your specialty pharmacy and medical providers early in the month to identify and resolve issues before they become an emergency.

Follow the guidelines as outlined above any time you reach out to your health plan. Working together at the start of a new plan year can make all the difference in maintaining uninterrupted access to the therapy and services keeping you healthy.

### **USEFUL LINKS:**

**Centers for Medicare and Medicaid Services:** Official website for the Centers for Medicare and Medicaid Services (CMS): <https://www.cms.gov/>

**E-Health Insurance Glossary:** eHealth provides a list of common insurance terms on their website: <https://www.ehealthinsurance.com/health-insurance-glossary/terms-c/>

**Employee Benefits Security Administration:** <https://www.dol.gov/agencies/ebsa>

**National Association of Insurance Commissioners (NAIC):** NAIC is a standard-setting and regulatory support organization. Their website includes a map that will allow you to determine the insurance commissioner in your state: <https://content.naic.org/>

**Patient Advocate Foundation:** The Patient Advocate Foundation (PAF) is dedicated to improving healthcare access. Their website offers education, assistance, and resources related to healthcare coverage: <https://www.patientadvocate.org/>

**United States Department of Labor:** Includes information on ERISA and COBRA plans: <https://www.dol.gov/general/topic/health-plans>

### **Reference:**

1. National Hemophilia Foundation. (2021). Comprehensive Medical Care. <https://www.hemophilia.org/healthcare-professionals/guidelines-on-care/comprehensive-medical-care>

# Hi Dad!

## A SON WITH HEMOPHILIA PAYS TRIBUTE TO HIS DAD

BY FELIX GARCIA

**Although I'm not an athlete, I always get a kick out of professional and college athletes who turn to the camera and say, "Hi Mom!" Often though, it's most likely their dad who taught them the sport, pushed them to exceed and helped them make decisions leading to that position. Yet, they all say, "Hi Mom!"**

It's funny to me! Let's be honest, it's such tradition now that if you didn't, even your dad would probably scold you, "What's the matter with you, son? Why didn't you give a shout-out to your mom?"

In the world of bleeding disorders, it's not much different except for my generation and many before me, it was all because of mom.

Mom taught us how to play the bleeding disorder game - she pushed us to infuse and coached us to not challenge our body beyond what it could do. And yes, she is probably the reason most of us are still here today. I speak from experience - well, at least from my own experience I should say!

I was one of the lucky few that grew up in the '70s and '80s with a dad who made sure I infused. He was great at it. He guided me and got me to infuse when I had to. Back then it was when I had an active bleed, prophylactic treatment was a dream and joint damage the reality.

Growing up, we didn't have local bleeding disorders meetings - in person or on Zoom. Hold on to your hats, kids... We didn't even have the Internet (please insert "shocked" emoji here)! This means I didn't have much to compare to until I was an adult and attended my first MANN meeting. For those of you too young to remember, MANN stood for Men's Advocacy Network of NHF, a group



founded in 1991 to bring together men with hemophilia and HIV/AIDS to advocate and provide support on a national level.

During these meetings, we shared childhood stories and myths and reminisced and joked about them. Though many of us had never talked before, we found we had many of the same superstitions. One that stood out was about not touching another needle beside the one you're going to use. If you did, you were destined to blow a vein and would then need the extra needle you touched. A room full of grown men and most of us were still afraid to touch another needle package. Sheesh!

**"...despite the pain, my dad still taught me how to be a man."**

Speaking with these other men, I also heard about the loving, devoted mothers in our community. I'd say more than 90% of the men raved about their moms. In the middle of the conversation, I decided to speak up and say how great my dad was. Wrong crowd. Few blood brothers held their dad in such high esteem as I did my father. Very few fathers had done the things my father did. Don't get me wrong, my mother did all those wonderful, self-sacrificing, noble acts that the others did too. She unselfishly dedicated her life to raising a child with a chronic illness.

My mom endured when told her 3-month old son had severe hemophilia and would not live past the age of 18. She survived his two major head bleeds that almost took his life, first when he was 18 months old and then again in his early 20s. She suffered greatly when told her 11-year-



old son was going to die of an AIDS-related illness because of the clotting factor they trustingly used. Yeah, my mom was just as big a rock star as any of those other mothers - she had her heart broken over and over because of me.

Well, so did my dad. He held my mom when no one else was around. He cried with her when the pain was too much to bear and he was her pillar of strength when that was what she needed. He chose never to give up no matter how many times his heart was shattered again and again with news that his son was going to die.

More importantly to me despite the pain, my dad still taught me how to be a man. He taught me that no matter how much he hated the sight of blood and needles, I could always count on him to infuse me or hold me in ER. He taught me whenever I had to be in the hospital after surgery, I still had to do my school assignments and read. He would show up with my homework and books.

He was always the one I wanted to impress with my recovery. My dad was always there for me. When I had to have surgery as an adult, my dad taught me that he would still always be there for me, taking my kids to school and helping my family around the house. And he is still the one I want to impress with my recovery.

I was lucky. Both my parents helped me become an adult who could manage his bleeding disorder. They both helped me become a better person. In my life, I was blessed with others who also mentored and helped me along the way. However, if having a bleeding disorder was a professional sport and the camera was on me for a brief

moment, to my dad and to all the dads that help make men of their boys with hemophilia, I would say, "Hi Dad. Thank you. I love you."

This is dedicated to all the parents who raised a child with a chronic illness and who underwent heartache and tears to get their children to where they are today. We don't always know when or how to say thank you and you may never know how deeply the appreciation extends, but words will never cover the moments you gave us, the life you preserved in us, and all the things we now as adults have come to realize.



# QUALITY TIME WITH YOUR KIDS

BY SARAH HENDERSON

We have learned a great deal this past year about not taking people for granted and making the most of every moment we have with those we hold dear. Quarantines, lockdowns, virtual learning and working from home have given us a mountain of time to be home with our loved ones. However, when we feel our time together seems endless, we may begin to take it for granted. Are you taking the time to spend true quality one-on-one time with your kids? Even though right now you likely have a vast *quantity* of time with them....is it *quality*? Here are some easy ways to make sure that the time you are spending together is quality:

- Have a specific day set aside that each child can look forward to- some people pick a specific day of the week, like every Tuesday, or a set date, such as the child's birth date. For example, a child born on the 12th would have their special one-on-one time on the 12th of each month. For busier or bigger families it may mean only one special day per month – but all the more important to stick with it and *make it matter*.
- Schedule your time as you would any other meeting and stick to it!
- Let your child know you are looking forward to your time with them.
- Turn monitors and screens off – be in the moment only with your child.
- Don't answer the phone. Let them know that they are your priority.
- Make your scheduled time all about your time with only that child – no other siblings, cousins, or friends. For older siblings, it could mean being with them after the younger children go to bed or are down for a nap. Maybe it means tag-teaming parents vs kids. The important thing is to figure out what works best for you and your family.
- Ask questions about their day, their interests and their dreams. Don't use this as a teaching moment or time to lecture – use it as a moment to listen, get to know them, and let them open up to you. Avoid topics that cause friction or conflict between you.
- Be flexible, be creative.

So much of our world today revolves around computer, phone, or television screens. Don't let these screens take away the value of your time together. It's also important not to fall into a cycle of trying to one-up or go over the top with activities and time spent together. Your time together should be something valued purely for the time spent, not money spent.



The options are limitless, but here are a few ideas to inspire you for screen-free entertainment:

- Go for a walk, bike ride, or roller skate
- Go for ice cream or make ice cream sundaes at home
- Throw a football or Frisbee around in the backyard
- Go fishing
- Go swimming
- Do a puzzle
- Have a picnic
- Bake a dessert together
- Play flashlight tag
- Play a board game
- Reminisce as you look through old photos together
- Build a snow fort and then hang out in it together
- Play basketball
- Make s'mores around a fire pit
- Teach your child a game you enjoyed when you were their age
- Learn a new art together – origami, painting, pottery
- Have a spa day
- Visit an animal shelter
- Try a new recipe and then enjoy eating it together
- Stargaze while enjoying a thermos of hot cocoa

An article in the Washington Post points out, "The more time a teen spends engaged with their mother, the fewer instances of delinquent behavior. And the more time teens spend with both their parents together in family time, such as during meals, the less likely they are to abuse drugs and alcohol and engage in other risky or illegal behavior. They also achieve higher math scores." Why not take advantage of this opportunity to spend time with your child? You will never get this time back and you'll never regret the time invested in a relationship with your child.

[https://www.washingtonpost.com/local/making-time-for-kids-study-says-quality-trumps-quantity/2015/03/28/10813192-d378-11e4-8fce-3941fc548f1c\\_story.html](https://www.washingtonpost.com/local/making-time-for-kids-study-says-quality-trumps-quantity/2015/03/28/10813192-d378-11e4-8fce-3941fc548f1c_story.html)

# Sign the 9 is now online!

Now it's easier than ever to make a difference.

Help make IXINITY® available to individuals in the United States who can't afford to be without it. It's easy. Just [visit signthe9.com](https://signthe9.com) and fill out a brief form. When you do, **9 IU of IXINITY will be donated in your name.** While you're there, build your own one-of-a-kind 9. Add your name, share your 9 on social media...and watch the support grow!



▶ Visit [signthe9.com](https://signthe9.com) today!

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**IXINITY®**  
coagulation factor IX  
(recombinant)

## Introducing the Points for Healthy Joints Program!



BioMatrix is pleased to announce a new program encouraging healthy behavior for bleeding disorder patients served by our specialty pharmacy. Starting in October, patients will earn points for healthy behaviors including turning in a monthly infusion log, completing a monthly assessment with a pharmacist, and attending an annual HTC visit. More behaviors will be added in the future. Every behavior carries a point value with each point representing entry to a monthly raffle including fantastic prizes.

Incentivizing behavior in the healthcare space is not a new concept. Many public and private health plans offer incentives

to members in order to encourage wellness and better health<sup>(1,2)</sup>. Research has demonstrated the effectiveness of these programs in promoting healthy behaviors<sup>(3)</sup>. The Points for Healthy Joints program will provide opportunities for patients to live healthy, earn points, and win prizes!

BioMatrix is committed to providing service and support making a difference for those living with a bleeding disorder. From education and community support to focused, individualized specialty pharmacy services, we work closely with patients, caregivers, HTCs, and other support organizations to make life a little easier.

Visit [biomatrixsprsx.com/bleedingdisorders](https://biomatrixsprsx.com/bleedingdisorders) to learn more about our specialty pharmacy services and to submit a no obligations referral today!

### Sources:

1. The Commonwealth Fund. (2020). Public programs are using incentives to promote healthy behavior. <https://www.commonwealthfund.org/publications/newsletter-article/public-programs-are-using-incentives-promote-healthy-behavior>

2. Migneault, J. (2017). Patient incentives from payers encourage preventative care visits. Health Payer Intelligence. <https://healthpayerintelligence.com/news/patient-incentives-from-payers-encourage-preventive-care-visits>

3. Adams, J., Giles, E., McColl, E., Robalino, S. (2014). The effectiveness of financial incentives for health behavior change: Systematic review and meta-analysis. Plos One. <https://doi.org/10.1371/journal.pone.0090347>

# BE AN ADVOCATE:

## THE INS AND OUTS OF MAKING ACCESS TO LIFE-SAVING MEDICATIONS A PRIORITY

BY SHELBY SMOAK, PhD

I've said this before, even in this newsletter, but I will say it again: Anyone with a chronic illness must become their own best advocate. Sometimes this advocacy comes in the form of promoting for our needs with a physician or other health care provider. To all the phlebotomists who I see several times in a year, I thank you for listening to my unending requests to use 23g needles over the much larger, standard 16g.

Advocacy is personal and constant. Sometimes however, advocacy requires more of a public, social dynamic. This article addresses that aspect, asking that everyone with an expensive chronic condition join in a push against the looming dominance of *Copay Accumulator Adjuster policies*.

116TH CONGRESS  
2D SESSION

### H. R. 7647

To provide for a COVID-19-related delay regarding annual limitation on cost-sharing for group health plans and individual and small group health insurance coverage.

IN THE HOUSE OF REPRESENTATIVES

JULY 16, 2020

Mr. MCEACHIN (for himself, Mr. RODNEY DAVIS of Illinois, and Mrs. WATSON COLEMAN) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Education and Labor, and Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned



Rep. Donald McEachin  
(D-VA)



Rep. Rodney David  
(R-IL)



Rep. Bonnie Watson  
Coleman (D-NJ)

As we move into the new year, we need to be wondering: Is there an accumulator adjuster policy in my 2021 insurance plan? Finding the answer and making a personal decision about your plan choice based on an accumulator adjuster is still an example of private, personal advocacy, and is of vital importance to your continued access to affordable health care.

In our last BioMatrix newsletter, we published a full spread on *Copay Accumulator Redux* and on navigating those in 2021. I won't revisit that information, but if you missed it, you can read it online at <https://www.biomatrxsprx.com/bleeding-disorders-publications> (BioMatrix News - Volume 15, Issue 4)

Let's take this piece of the insurance forward and consider how you can transform personal advocacy on copay accumulators into state and national advocacy.

### WHY SHOULD I ADVOCATE FOR ENDING COPAY ACCUMULATOR ADJUSTER INSURANCE POLICIES?

There are several reasons 2021 should be a year to advocate against copay accumulator adjuster policies:

1. New rules have allowed insurers to apply these policies more freely and widely, making it more likely community members will be impacted.
2. Accumulator policies can make medicines unaffordable for many families, putting their health at risk.
3. Accumulator policies can jeopardize the financial well-being of a family, forcing them to choose between paying for life-saving medicines or for food or bills.
4. Advocacy will be required at the state and federal level, as these oversee different insurance plans.

5. There is currently no other issue that would perhaps put people with chronic illness at greater financial or health risk than this.
6. Advocacy here helps you, your family, and everyone in the rare disease community who depend on medications without generic alternatives.

## HOW DO I BECOME A STATE ADVOCATE?

A great place to start flexing your advocacy is at the state level. Already four states—Virginia, West Virginia, Illinois, and Arizona—have passed copay accumulator bans, all of which were achieved through advocacy. Here in Virginia where I live, the local bleeding disorder chapters [Virginia Hemophilia Foundation and Hemophilia Association of the Capital Area] pushed our community to contact our state legislators about the copay bill under consideration. They made this a priority during their advocacy days, and they partnered with other rare disease groups to create a LOUD and resounding voice against the copay accumulator adjuster.

This type of advocacy depends upon volume and numbers, so while you may sometimes feel adding your voice may not matter, that is just not true. This kind of thinking falls into a classical paradox known as the *Sorites Paradox*, or, more commonly, *The Argument of the Heap*. The paradox claims that 1 person removed or added to a group doesn't matter, but the paradox is that group, the heap, really doesn't exist: a heap is simply a term for the collection of individual parts, each independent but essential. Removing or adding an individual to that heap substantially changes it. If you've lost me on the philosophy there, it's really just to say everyone matters and in advocacy, every voice matters.

### Here are a few steps for taking state action:

#### 1. Reach out to your local chapter and ask about any pending copay accumulator state bills.

If your state doesn't have a current bill under consideration, ask about a group or coalition that may be drafting or seeking sponsorship for a bill. You may also reach out to HFA and NHF who have policy divisions following issues at a state level. The education team here at BioMatrix is also a great resource. We have contacts in each state who follow this issue and would be happy to relay the information to you. Just email us at [education@biomatrixsprx.com](mailto:education@biomatrixsprx.com).

#### 2. Use an online tool to find and contact your state legislators.

There are several online tools for finding your representatives if you google "find my representatives" and enter your state, but HFA has a great one on their website, [www.hemophiliafed.org](http://www.hemophiliafed.org). On their site, hover your cursor over "For Patients and Families" and click "Take Action Center." From there, scroll down until you see "Find My Legislator." Enter your information and the tool will show all your representatives from a national



and state level. HFA even provides direct links to your representative pages where you can email them and also sign up for their office's newsletters to keep you even more informed.

#### 3. Write a short email asking to support a bill if your state has one pending.

Check out our handy template at the end of this article for advice on writing this.

#### 4. Write to your state representative about sponsoring a copay accumulator bill if none is pending.

Unfortunately, this is where things start and would indicate your state advocacy has a bit more work to do. Don't be disheartened if this is the case; all current laws started here, and all bills also start here. However, be sure you have reached out to your chapter or a group like HFA to find coordinated efforts that may be going on. Often on issues like this, certain state legislators will already be indicated as favorable to supporting a bill and that's where you'd want to focus these initial energies. This may be a representative other than your own. Once a sponsor is secured, you work up the ladder to bring more representatives on board supporting the cause.

## HOW DO I BECOME A NATIONAL ADVOCATE?

Advocacy at the national or federal level is very similar to that at the state level. The key steps are essentially the same except you will now be reaching out to your Congressional House and Senate representatives. Moreover, there is already a bill in the House that needs support!

1. Use an online tool to find and contact your Congressional House representative via email or phone. See above for advice.
2. Ask your House representative to support House bill HR 7647. This bill, introduced by Rep. Donald McEachin (D-VA), Rep. Rodney David (R-IL) and Rep. Bonnie Watson Coleman (NJ-12) delays the implementation of copay accumulator adjusters for 12 months beyond the end of the COVID-19 pandemic. While the bill does not seek to terminate copay accumulator policies as many of us

# ADVOCACY LETTER TEMPLATE

This template serves as an example of how to write to a legislative representative regarding HR 7647. Try to keep your letter to one page, be polite, be specific, and share your personal story.

## GREETING

*(Use "Dear" as it is best accepted formal greeting and use titles, which can be shorten to Rep. or Sen.)*

Dear Representative \_\_\_\_\_ or Senator \_\_\_\_\_ :

## OPENING

*(Be polite and direct about why you are writing. Change to suit your needs. Keep it short and to the point - 2-3 sentences.)*

I am writing to ask for your support of **HR 7647**. I (my child, my loved one, etc.) have (has) \_\_\_\_\_ (severity and diagnosis), which is a rare bleeding disorder. My hemophilia (or other diagnosis) is treated with (medication name), an extremely expensive medication used to control bleeding – there is no generic form of this (injectable) medicine. I rely on manufacturer copay cards to help pay for my life-saving medication, but insurance company **copay accumulator policies** have made my medication difficult to afford. **HR 7647** addresses this issue and would allow me to receive the vital medicine I (my child) need(s).

## BODY

*(The body of the letter needs to include your personal story. Listed below are some tips to help provide content. Be specific and provide an example. Keep this to 2 paragraphs, 4-6 sentences each.)*

### Paragraph 1

- How long have you had/cared for someone with hemophilia/vWD and how long have you been reliant upon life-saving medicine?
- On average, how much does your medication cost per month/per year?
- How much is your yearly deductible and out-of-pocket?
- Explain how being able to use a copay card in the past made a difference - when you ordered, used the card, and were able to receive medication.
- Explain why you may be unable to obtain this medication without the help of a copay card being applied toward meeting your out-of-pocket.

### Paragraph 2

- Speak about what would happen to you/your child without bleeding disorders medication.
- If you have an example where medicine saved your/your child's life or prevented serious ramifications, include it in a few sentences. This paints a human portrait for your legislative representative.

## CLOSING

*(Keep it short and direct. Restate the bill you would like your legislator to support and thank them.)*

- This is a very expensive disease whose outcome would be disabling or even fatal without life-saving medicines.
- The financial burden and affordability of treatment has become increasingly difficult/impossible due to insurance companies' **copay accumulator policies**.
- Thank you very much for your consideration and time.
- Please feel free to contact me for more of an explanation on how **HR 7647** affects me. I look forward to hearing from you.

## SIGNATURE

*Include all of your contact information. While it's unlikely you will be called, you just might. Include your address as it will confirm your constituency.*

Sincerely,  
Name  
Address  
Home and cell phone  
Email



would like, it is a politically savvy move to try and recruit bipartisan support, for which HR 7647 congressional representatives on both sides can feel good about supporting a temporary delay related to the pandemic as opposed to a full commitment to overturning an insurance policy. As advocacy goes, it would give the community a foothold in the argument if HR 7647 were to pass.

3. Contact your Senate representative and let them know about HR 7647 and ask for a companion Senate bill, and/or for support for HR 7647 when it leaves the House.
4. Continue following up with both representatives throughout the year. Here, you must walk the balance between concerned advocate and over-zealous disruptor; in other words, you wouldn't want to email your representatives daily, but once is not enough to show them your concern. I like to say you should be polite and courteous and follow up just to be "annoying enough," perhaps every month or so.

### **WHY SHOULD I PARTICIPATE IN STATE AND NATIONAL ADVOCACY?**

For an issue like copay accumulator adjusters, it's imperative to participate in advocacy at the state and national level as the laws you are seeking would cover accumulator policies in different plans. State laws will offer protections from accumulator policies in state-run and ACA plans, but they will not protect people enrolled in large group plans, such as those found in big companies that have employees in more than one state. National, federal law, however, will cover accumulator policies in those large group insurance plans, but, likewise, will be ineffective for state-run plans.

### **WHEN SHOULD I START?**

Now! Today! The right time is always right now!

### **WHAT IF I'M NOT A GREAT WRITER OR SPEAKER?**

This doesn't matter. Representatives hear from hundreds of thousands of constituents just like you. Follow the ABCs here and you'll be fine:

1. Tell your story about how life-saving medicines are important to you or a loved one.
2. Explain to your representative why copay accumulator adjusters are dangerous to you or your loved one.
3. Ask them to support a bill against copay accumulator adjusters.

That's it! Your voice will be heard, and advocacy will do its job of improving our lives and our health!



# **Assisting Educating Advocating For The Bleeding Disorders Community.**



[www.hemophiliafed.org](http://www.hemophiliafed.org)

# BIOMATRIX

## Meet the Team!



**LeAnn Wilson**  
Regional Care Coordinator

BioMatrix is dedicated to making a difference in the bleeding disorders community. Our team of Regional Care Coordinators and Patient Care Specialists provide support that draws on personal experience and a genuine commitment to the bleeding disorders community. Our “Meet the Team” segment invites you to get to know our incredible staff a little bit better.

In this edition, we feature LeAnn Wilson!

**“When patients are empowered, their lives change. My number one goal is to empower patients while providing family-focused support that improves quality of life and makes a difference for the bleeding disorders community.”**

LeAnn Wilson has been an active member of the bleeding disorders community since 2008 and has served in her role as a BioMatrix Regional Care Coordinator since 2016. She primarily serves patients in Tennessee, Mississippi, Arkansas, and Louisiana. LeAnn was born, raised and still happily resides in Bethel Springs, Tennessee, with her husband Adam of 19 years and their two children, Hunter and Haylee. In addition to spending time with her family, she enjoys the outdoors, crafting, singing and cheering on her kids as they do what they love!

As a mother of a son with severe hemophilia, she attended many local chapter events and began organizing fundraising activities to give back to the community. With a degree in business management, LeAnn uses her personal and professional experience to provide exceptional service to the families and individuals she works with.

### **What is your connection to the bleeding disorders community?**

In April of 2008, we were thrown into the world of bleeding disorders two days after my son was born when his circumcision began to bleed excessively. My pediatrician ran some tests and asked if there was any family history of bleeding disorders, which there was none. The doctor returned with the lab results and confirmed my son had hemophilia A. My parents and those of my husband immediately gathered at the hospital. The doctor told us she didn't know much about hemophilia but proceeded to give us a very brief explanation. She explained the baby would be given clotting factor and then transferred to St. Jude's Hospital. After 3 hours of trying and 28 sticks, the clotting factor was finally administered.





Graduation



LeAnn's inspirations, Hunter and Haylee



Enjoying time outdoors

### How did you react to your son's diagnosis?

My son's diagnosis of severe hemophilia A was very difficult for me. I found myself very depressed and fearful. These feelings lasted for about a month.

### How did you overcome your initial fears?

I overcame my initial emotions by educating myself on how to best care for him and leaning on my support group, which consisted of our parents, my pharmacy rep and especially a nurse at St. Jude. The nurse gave me a lot of reading material and was very patient with my constant questions. She showed great compassion even when I called fearing I had clipped my son's nails and nipped his skin. The nurse and my pharmacy rep were always available to answer my many questions. Their support and kindness were crucial to me.

Early on, I learned the importance of connecting with others in the community, gaining knowledge and insight from my peers and applying what I learned to support my family. I even completed a phlebotomy course to gain a deeper insight and understanding for peripheral infusions.

### As a Regional Care Coordinator, how do you feel you are Making a Difference?

I aspire to make a difference by helping address the range of needs bleeding disorder community members require. I connect and encourage patients to engage the clinical resources at their disposal while providing emotional and peer-support for families as they navigate life with a bleeding disorder. I stay actively involved with the community in my role as a Care Coordinator and on a personal level as well.

### What is one of your proudest achievement?

In 2020, I was recognized by the Tennessee Hemophilia and Bleeding Disorders Foundation with the "Volunteer of the Year" award. I want to give back and support my community in any meaningful way possible and would do so regardless, but to receive the award was such an honor!

### Do you have a favorite quote?

My favorite quote is "Knowledge is Power" and that is my goal, to empower members of our community with the knowledge and support to properly care for themselves, their family and their loved ones.

### What would you say to a newly diagnosed family?

Just breathe. Take a minute and relax. I don't sugar coat things and say it's all going to be easy, but I tell new parents that they will be okay – they are stronger than they know and they will get through this.

Especially to new mothers, I advise them to step away a bit and to be sure to take care of themselves. It's easy to get lost in caring for others with no regard for yourself. Taking a bit of time for oneself helps balance life and makes for a better caretaker. I also advise parents to educate themselves as well as their loved ones and to set those nearest to them as a source of support and to share in emotions.

### Contact LeAnn:

Mobile: 731-610-5034

Email: leann.wilson@biomatrixsprx.com

*Congratulations!*

**Congratulations to our own LeAnn Wilson for her recognition as the Tennessee Hemophilia & Bleeding Disorders Foundation 2020 Volunteer of the Year!**

LeAnn was honored for her involvement and leadership in chapter programming including 3 years of participating on the annual meeting committee and coordinating the THBDF's Women's Rap Session. She was recently honored at the chapter's virtual annual meeting where she was presented her award.

**Congratulations, LeAnn!**




Ready to advocate on Capitol Hill!

# MY DECIDING FACTOR:

*Making time for what matters most.*

**vonvendi**  
[von Willebrand factor  
(Recombinant)]

Erica  
Surprise, AZ  
Diagnosed with VWD in 1981

**Are you ready to ask about  
VONVENDI for your VWD?  
Visit [VONVENDI.com](https://www.vonvendi.com) to  
learn more.**

As an adult living with von Willebrand disease (VWD), you may share a bleeding disorder with others, but you have your own life, and your own needs. You may also have your own Deciding Factor—something that drives you to talk to your healthcare provider about finding a treatment that's right for you. For Erica, it was that her frequent bleeding episodes were taking time away from things that mattered most to her. She talked with her healthcare provider, and together they decided that VONVENDI® [von Willebrand (Recombinant)] was right for Erica's VWD.

## VONVENDI

- Is used in adults (age 18 and older) diagnosed with VWD to **treat and control bleeding episodes** and **prevent excessive bleeding during and after surgery**
- **Is the first and only recombinant von Willebrand factor (VWF)**, meaning it is manufactured without human plasma or blood
- **May be used with or without a recombinant factor VIII (rFVIII)**, as instructed by your healthcare provider

## VONVENDI Important Risk Information

### Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

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

**Please see additional Important Risk Information below.**

## Important Risk Information (continued)

### How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider. Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

### What should I tell my healthcare provider before I use VONVENDI?

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 VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

### What else should I know about VONVENDI and von Willebrand disease?

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

### What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

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.

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider 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](https://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.**



## Important facts about VONVENDI®:

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

  
**[von Willebrand factor  
(Recombinant)]**

### What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery

### Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

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

### What should I tell my healthcare provider before I use VONVENDI?

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 VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

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

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

### What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

### What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI 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 healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at [https://www.shirecontent.com/PI/PDFs/VONVENDI\\_USA\\_ENG.pdf](https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf) or call 1-800-828-2088.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

Issued 02/2019

S48947 06/19

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# BIOMATRIX

## ON THE *Virtual* MOVE!

Though we're not yet on the physical "move," we've been busy hosting all sorts of fun-filled and informative educational Zoom meetings! Read on to see what we've been up to. Plan on joining us soon!

### #BioMatrixMugClub

Curl up with your favorite warm beverage and BioMatrix virtual programming! BioMatrix offers a variety of educational and entertaining topics in small or large groups and in individual settings. All program participants receive one of our fantastic coffee mugs along with a few other useful items!

Have you participated in BioMatrix educational programming? Post a photo using the hashtag [#biomatrixmugclub](https://www.instagram.com/biomatrixmugclub).

Visit us to learn more!

<https://www.biomatrixsprx.com/bleeding-disorders-education>

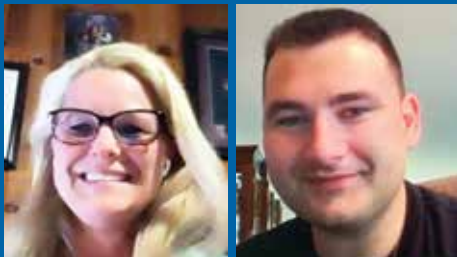


# Transition TO SELF-INFUSION

Learning to self-infuse can be very powerful as patients take charge of their bleeding disorder treatment. In this session Kelly Gonzalez and HTCNV nurse Becki Berkowitz presented a clear view of how to infuse your own factor. The session addressed the benefits of being able to self-infusion at home, school, or work, and gave helpful tips while Kelly demonstrated an infusion.

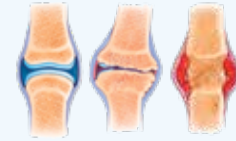


**OCTOBER 1, 2020**  
Presenter/RCC: Kelly Gonzalez  
Host: HTC of Nevada  
Sponsor: Octapharma



For information about our educational sessions or to schedule a session for your group (large or small!), please contact us at:  
(877) 337-3002 ext. 1515  
<https://www.biomatrixsprx.com/contact>

## No Need To Bleed: Making Joints Last A -Lifetime-



This session highlighted the negative effects of bleeding episodes on the joints and demonstrated the need for therapy adherence and access for people with a bleeding disorder. This program offered hard hitting facts about the benefits of prophylactic treatment versus treating on demand.

**SEPTEMBER 12, 2020**

Presenter: Terry Rice  
RCC: Justin Lindhorst  
Host: Kentucky Hemophilia Foundation, Virtual Camp Discovery

**NOVEMBER 12, 2020**

Presenter: Shelby Smoak  
RCC: Justin Lindhorst  
Host: Florida Association of Pediatric Tumor Programs

## Women Bleed Too

**SEPTEMBER 18, 2020**

Presenter: Kelly Gonzalez  
Host: Utah Hemophilia Foundation Women's Group

Our *Women Bleed Too* program discussed the signs and symptoms, and the difference between a *symptomatic carrier* versus a *women with a bleeding disorder*. Kelly Gonzalez discussed how a bleeding disorder can affect your life, the importance of keeping a journal, and how to open dialogue with a provider.

## Awareness for -Advocacy-

**SEPTEMBER 18, 2020**

Presenter/RCC: Kelly Gonzalez  
Host: UT Hem Women's Utah Hemophilia Foundation (UHF)

**SEPTEMBER 25, 2020**

Presenter/RCC: Kelly Gonzalez  
Host: Connecting Community Retreat  
Sponsor: Octapharma

**NOVEMBER 18, 2020**

Presenter: Terry Rice  
RCC: Peggy Klingmann and PCS: Mary Foertsch  
Sponsor: Bayer

Session highlighted the need for record keeping, health literacy and tools when faced with challenges such as appeals, denials and problems with access to care.

## Putting The Mask On -First-

**SEPTEMBER 25, 2020**

Presenter/RCC: Kelly Gonzalez  
Host: Connecting Community Retreat  
Sponsor: Octapharma

This meaningful session brought attention to the needs of caregivers for people with a chronic illness.

**OCTOBER 2, 2020**

Presenter: Terry Rice  
Comms Manager: Maria Santucci Vetter  
Host: The Coalition For Hemophilia B  
Sponsor: Medexus

## — Navigating — Open Enrollment

**NOVEMBER 5, 2020**

Presenter: Shelby Smoak

Provided an overview of the insurance open enrollment period for private-employer, government, and ACA marketplace plans. This session offered an understanding of 2021 insurance policies and their impact on patients.

## — CO-PAY — Accumulators

**NOVEMBER 17, 2020**

Presenter: Terry Rice

This session offered a deep dive into Co-Pay Accumulators and how they may affect patients in the bleeding disorders community.

## Did you know?

If you attend our educational and fun Zoom events, you can have your name entered into a raffle for a \$50 gift card. When we reach 50 attendees, we draw a winner!

## Raffle Winners of 2020!

May 19 Alexander King	June 30 Timothy Wilcox	Aug 28 Najmun Nahar	Oct 7 Julia Mora
June 2 Milinda DiGiovanni	July 22 Regly Acosta	Aug 28 Darlene Trice	Dec 8 Laura Portales
June 9 Tara Lutz	Aug 11 Gabi Muncy	Sept 16 Diane Gassiraro	Dec 15 Dave Alderete
June 18 Phil Monin	Aug 11 Laura Portales	Oct 1 Nicole Padilla	Dec 15 Cynthia Ramirez

### BIOMATRIX GAME NIGHT

Looking for fun?  
Join us for a future Game Night!



#### SEPTEMBER 17, 2020

Family Feud

Presenter: Shelby Smoak  
RCC: Michelle Stielper  
Host: VHF

#### SEPTEMBER 19, 2020

Trivia!

Presenter: Terry Rice  
RCC: Justin Lindhorst  
Host: KHf Camp Discovery

#### OCTOBER 1, 2020

Loteria ¡En español!

Presenter: Shelby Smoak  
RCC: Felix Garcia  
Host: HOELP

#### OCTOBER 28, 2020

Loteria ¡En español!

Presenter: Shelby Smoak  
RCC: Eva Kraemer  
and Felix Garcia

#### OCTOBER 28, 2020

Loteria ¡En español!

Presenter: Shelby Smoak  
RCC: Eva Kraemer  
and Felix Garcia

#### NOVEMBER 7, 2020

Jeopardy

Presenter: Shelby Smoak  
RCC: Rich Vogel  
Host: CFS

#### NOVEMBER 12, 2020

Jeopardy

Presenter: Shelby  
PCS: Carri Nease  
Host: CHES Inhibitor Mtg

#### DECEMBER 4, 2020

Loteria ¡En español!

Presenter: Shelby Smoak  
RCCs: John Martinez  
and Gabriela Griffin

#### DECEMBER 4, 2020

Trivia

Presenter: Shelby Smoak  
RCC: Terry Stone  
Host: VHF

#### DECEMBER 5, 2020

Trivia

VHF Holiday Gathering  
Presenter: Shelby Smoak  
RCC: Terry Stone

#### DECEMBER 5, 2020

Loteria ¡En español!

Presenter: Kelly Gonzalez  
RCC: John Martinez  
Host: HFNC

30 YEAR ANNIVERSARY  
THE COALITION FOR  
HEMOPHILIA B

9 MEETINGS | 50 STATES | 1 BIG FAMILY

A meeting for patients & families with Hemophilia B

GET YOUR 30TH ANNIVERSARY LIMITED EDITION  
T-SHIRT & REGISTER AT HEMOB.ORG



# THE GREAT *Midwest* JEOPARDY CHALLENGE



Shelby Smoak



Eva Kraemer



**Bridgit Tyrey**  
Gateway Hemophilia  
Association



**Angela Brown**  
Midwest Hemophilia  
Association



**Michael Towner**  
Bleeding Disorders  
Alliance Illinois

**On November 19, 2020, two legendary Executive Directors and one Board of Directors President battled it out on Zoom bleeding disorder's JeoParody Challenge in a very spirited competition. Thank you to our sponsor, CSL Behring.**

Angela Brown from Midwest Hemophilia Association (MHA), Bridgit Tyrey of Gateway Hemophilia Association (GHA) and Michael Towner of Bleeding Disorders Alliance Illinois (BDAl) represented their chapters with their expertise as the challenging competition tested their bleeding disorders knowledge.

Our host was none other than Shelby Smoak, Ph.D. who, with his sidekick Regional Care Coordinator Eva Kraemer, guided the contestants into a feisty, yet friendly competition as community members offered lifelines to their respective chapters. Everyone's bleeding disorders knowledge was put to the test as the audience cheered and gained invaluable education during the event.

CSL Behring was a proud sponsor of the amazingly fun-filled evening. Angela Brown (MHA) edged ahead of her competition and claimed the title, the trophy, and the bragging rights as the winner of the Midwest JeoParody Challenge!

We formally invite all Executive Directors who want to take up the challenge! Organize a group of like-minded executive directors and reach out to BioMatrix at [education@biomatrixsprx.com](mailto:education@biomatrixsprx.com). Let the games begin!



And the winner is...  
**ANGELA BROWN**  
MHA Executive Director!



# Feed Mind + Body — WITH CHEF MIKE! —

Mike Hargett is a professionally trained chef, double transplant recipient, and a person with hemophilia. He has gained fame within the bleeding disorder and transplant communities as a fantastic cooking demonstrator. Chef Mike shares his enthusiasm for cooking and his “zest” for life as he elevates ordinary household ingredients into savory, restaurant-enviable meals. As the world’s first person with hemophilia to receive a heart and a kidney transplant, Mike’s positive attitude, good-humored personality, passion for cooking, and perseverance embody his spirit of “cooking with heart.”



**SEPTEMBER 24, 2020**

**¡En español!**

*Open Enrollment and Insurance*

Presenter: Kelly Gonzalez

RCC: Gaby Griffin

**SEPTEMBER 26, 2020**

*Putting the Mask on First*

Presenter: Terry Rice

RCC: Jeff Johnson

**SEPTEMBER 29, 2020**

*It's OK to Not be OK*

Presenter: Terry Rice

RCCs: Rania Salem and Eva Kraemer

**OCTOBER 21, 2020**

*Putting the Mask on First*

Presenter: Kelly Gonzalez

RCC: Richard Vogel  
Host: Hemophilia Association of New Jersey

**OCTOBER 24, 2020**

*Putting the Mask on First*

Presenter: Kelly Gonzalez

RCC: Jeff Johnson

**OCTOBER 27, 2020**

*Open Enrollment*

Presenter: Kelly Gonzalez

RCC: Cyndy Coors  
Host: Blood Disorder Center at TC Thompson Children's

**OCTOBER 29, 2020**

*Putting the Mask on First*

Presenter: Kelly Gonzalez

RCC: Jeff Johnson

**OCTOBER 29, 2020**

**¡En español!**

*Putting the Mask on First*

Presenter: Kelly Gonzalez

RCC: John Martinez

**NOVEMBER 19, 2020**

*Putting on the Mask First*

Presenter: Kelly Gonzalez

RCC: LeAnn Wilson

**NOVEMBER 21, 2020**

*Putting on the Mask First*

Presenter: Kelly Gonzalez

RCC: Jeff Johnson

Sponsor: Octapharma

**DECEMBER 8, 2020**

*Putting on the Mask First*

Presenter: Terry Rice

RCC: Richard Vogel  
Sponsor: Novo Nordisk

**DECEMBER 9, 2020**

*Putting on the Mask First*

Presenter: Terry Rice

RCC: Tina McMullen

**DECEMBER 15, 2020**

*Copay Accumulator Adjustor*

Presenter: Shelby Smoak

RCC: Richard Vogel  
Host: New York Chapter Hemophilia Chapter

**DECEMBER 17, 2020**

*Putting on the Mask First*

Presenter: Terry Rice

Comms Manager: Maria Santucci Vetter  
Host: The Coalition For Hemophilia B  
Sponsor: Medexus

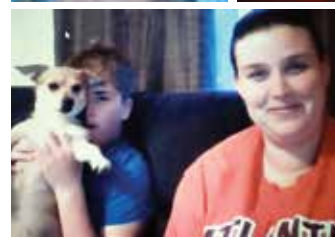
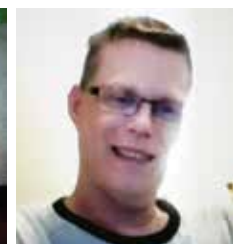
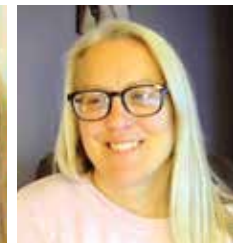
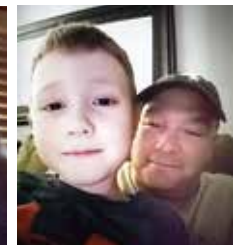
**DECEMBER 19, 2020**

*Feed Mind & Body with Chef Myles!*

*Putting on the Mask First*

Presenter: Terry Rice

RCC: Jeff Johnson  
Sponsor: Medexus





*Learning from the talented Chef Mike!*



Below are a few of the delicious dishes Chef Mike has featured. Want a copy of a recipe? Contact your Regional Care Coordinator or email us at: [info@biomatrixsprx.com](mailto:info@biomatrixsprx.com)

- Asian Sticky Roasted Chicken Wings
- Bada Bing Chicken à la King
- Best Grilled Chicken in the World
- Best Mushroom Risotto in the Universe
- Chicken and Broccoli Cheesy Pasta with Bacon
- Easy Peasy Gnocchi Mac and Cheese with Spinach
- Pan-Seared Chicken Thighs with Caramelized Apple and Onion Pan Sauce
- Pan-Roasted Pork Chops with Apple and Sweet Onion Jus with Mashed Root Vegetables
- Winner Winner Green Chicken Chili Dinner and White Cheddar Cornbread Muffins



- Dry-Sauteed Green Beans
- Garlic and Herb Smashed Potatoes with Sour Cream and Onion Sauce
- Ginger-Scallion Rice
- Better Than Olive Garden's Salad
- Grandma Rosie's Marinated Tomato, Cucumber and Onion Salad
- Shaved Brussels Sprouts Salad with Dried Cherries, Aged White Cheddar and Toasted Almonds
- Fall in a Glass - aka Mulled Apple Cider
- Peach Bellini Raspberry Iced Tea
- Sparkling Holiday Cranberry Limeade



*Time for Fun!*

**ANSWERS TO PUZZLES ON PAGE 31**

1. P O R T  
 2. S Y R I N G E  
 3. P R O P H Y  
 4. I N F U S E  
 5. F A C T O R  
 6. N E E D L E  
 7. B L E E D  
 8. V E I N

7	8	1	6	2	3	4	1	8	7
5	9	6	2	3	4	1	8	7	
4	8	2	9	1	7	6	5	3	
3	7	1	6	5	8	2	9	4	
7	3	4	5	9	1	8	2	6	
8	5	3	7	4	2	6	9	1	
2	7	9	1	5	6	8	4	3	
6	4	1	3	8	9	7	5	2	
3	8	2	9	6	7	5	1	4	
4	1	5	8	2	3	9	6	7	
9	6	7	4	1	5	3	2	8	
2	4	9	1	7	3	5	6	8	

# SHOOTING FOR STRONG ON-DEMAND BLEED RESOLUTION, THIS NHL HEAD COACH CHOSE IDELVION

David Quinn has had an incredible and inspiring journey on his road to becoming head coach of the New York Rangers. David attributes finding his coaching passion to his hemophilia B diagnosis.

**IDELVION provides David with strong bleed resolution when treating his hemophilia B on-demand.**



Learn more about effective on-demand bleed resolution at **IDELVION.com**

**“I chose IDELVION because I have confidence in the product and I have confidence in CSL Behring”**

—David Quinn, Head Coach of the New York Rangers

## Important Safety Information

IDELVION® (Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP)), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION. **Please see brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call **1-800-FDA-1088**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

\*Hemophilia FIX Market Assessment, Third-Party Market Research.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Lengnau AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

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www.CSLBehring.com www.IDELVION.com IDL-0523-SEP20

**IDELVION®**  
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

**IDELVION®**, Coagulation Factor IX (Recombinant), Albumin Fusion Protein  
Initial U.S. Approval: 2016

**BRIEF SUMMARY OF PRESCRIBING INFORMATION**

These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

**What is IDELVION?**

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

**Who should not use IDELVION?**

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION, or are allergic to:

- hamster proteins
- any ingredient of IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

**What should I tell my healthcare provider before using IDELVION?**

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told
- you have (because IDELVION might not work for you)

**What must I know about administering IDELVION?**

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. (**For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.**)
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

**What are the possible side effects of IDELVION?**

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

**Based on October 2019 revision**

**Please see full prescribing information, including FDA-approved patient labeling.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.**

## Singing <sup>to</sup> HEAL

This session empowered participants to tap into the healing power of music and share the emotional experience with others. It briefly covered music's history, scientific facts of music's positive affect on our brain, how it may help with pain control, and how it can help heal the soul and change our mood one note at a time.

**SEPTEMBER 24, 2020**

Presenter: Terry Rice  
RCC: Susan Moore

**NOVEMBER 8, 2020**

Presenter: Shelby Smoak, Ph.D.  
RCCs: Michelle Stielper and Terry Stone  
Host: Virginia Hemophilia Foundation Men's Retreat

**NOVEMBER 18, 2020**

Presenter: Shelby Smoak, Ph.D.  
RCC: Richard Vogel  
Host: New England Hemophilia Association

**DECEMBER 16, 2020**

Presenter: Shelby Smoak, Ph.D.  
RCC: Richard Vogel  
Host: New England Hemophilia Association



## Navigating TRICARE



For community members in the military, this session offered an overview of TRICARE and an examination of the obstacles to continuity of care. Information regarding enrollment, coverage, the necessity of TRICARE pharmacy-approved status for factor medications, and support resources available was all included.

**NOVEMBER 10, 2020**

Presenter: Shelby Smoak  
RCC: Justin Lindhorst

## Transition TO SCHOOL



This important session provided guidance to parents and caregivers of school-aged children diagnosed with a chronic disorder. It included details regarding educational rights and information on establishing a 504 Accommodation Plan.

**SEPTEMBER 18, 2020**

Presenter: Kelly Gonzalez  
Host: Utah Hemophilia Foundation Women's Group

# 'Twas the Night

## Holiday Celebration



BioMatrix would like to thank everyone who joined us for our Holiday celebration, *'Twas the Night*, where we gathered via Zoom from our warm cozy homes on two nights, December 9th and 10th, to herald in the holiday season.

A special *thank you* to everyone who took time out of their busy evenings to join us in these joyous and festive diversions to our daily life. Whatever or however you celebrated the season, BioMatrix wishes you peace, joy, and good health!



'Twas the holiday season and all through the land  
There were masked faces and curfews and temperature scans.

When what to our weary eyes should then appear?  
A BioMatrix notice to join for holiday cheer!

They came from all over, they zoomed from afar.  
Coming with happy faces rather than a plane or car.

The kids slayed the trivia, they sang and laughed.  
Oh, and of course Santa was there with his sweet, better half!

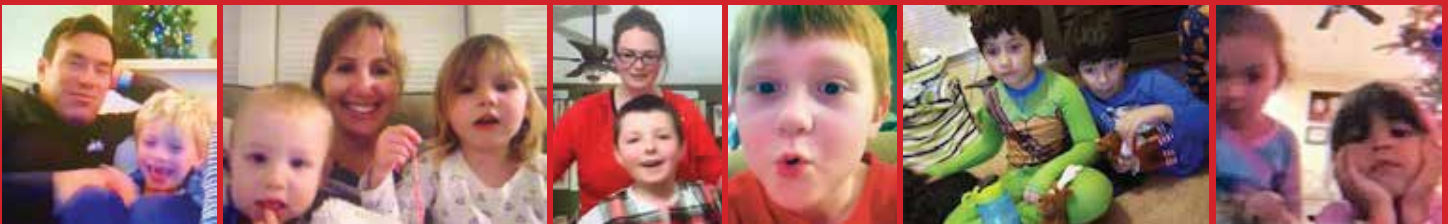
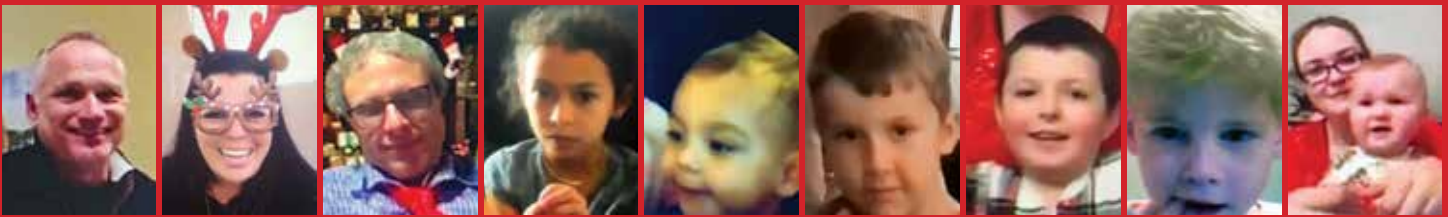
From their workshop up north, Santa and Mrs.  
Read their favorite story, 'Twas the Night Before Christmas.

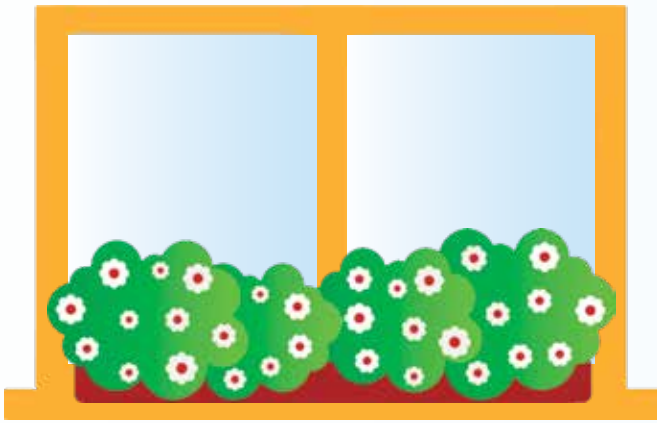
Reindeer Rudaphne kept the party going,  
While game show host Shelby kept the trivia flowing.

Then last but not least, sweet carols filled the air.  
The sound of an angel, Terry Rice's voice is so rare.

We busted a move with a dance party groove.  
It was fun, it was festive, some weary hearts it did sooth.

Christmas, we learned, doesn't come from a store  
Maybe the holidays, perhaps, mean a little bit more.





# Time for Fun!

## Window Box Fun!

Hidden in Column 1 are words pertaining to bleeding disorders. Match up the window panes in Column 2 to reveal the hidden words. We've done the first one for you. Answers are on page 29.



### COLUMN 1

1. P X O S R B T O G S D.
2. S L Y S R I N L G E \_\_\_\_\_
3. B P R N F O P H B Y \_\_\_\_\_
4. P I N K F U J N S E \_\_\_\_\_
5. F W A D V C T O R E \_\_\_\_\_
6. D P N E N E D X L E \_\_\_\_\_
7. B L K S U E E H F D \_\_\_\_\_
8. M V R E L I P N A Y \_\_\_\_\_

### COLUMN 2

- A. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- B. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- C. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- D. P O R T [ ] [ ] [ ] [ ] [ ] [ ]
- E. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- F. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- G. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]
- H. [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

	4		1	7	3		6	
				2		9		1
1	5	7	8			3		
		8		4	6			5
6	1	5					3	9
7			5	9		8		
		1			8	2	9	4
4		2		1	7	6	5	3
	9			3	4			

**Sudoku!**  
Fill in the grid so every row, every column, and every 9 by 9 box contains the numbers 1 through 9.

9		7	4			3		
		5		2	3			7
3			9	6		5		4
6	4	1	3				5	
	7			5			4	
	5				2	6	9	1
7		4		9	1			5
5			2	7		1		
		6			8			9

# BIOMATRIX

## Corporate Office

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Office: 954-385-7322

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## Visit us online:

[bleedingdisorders.biomatrixsprx.com](http://bleedingdisorders.biomatrixsprx.com) 

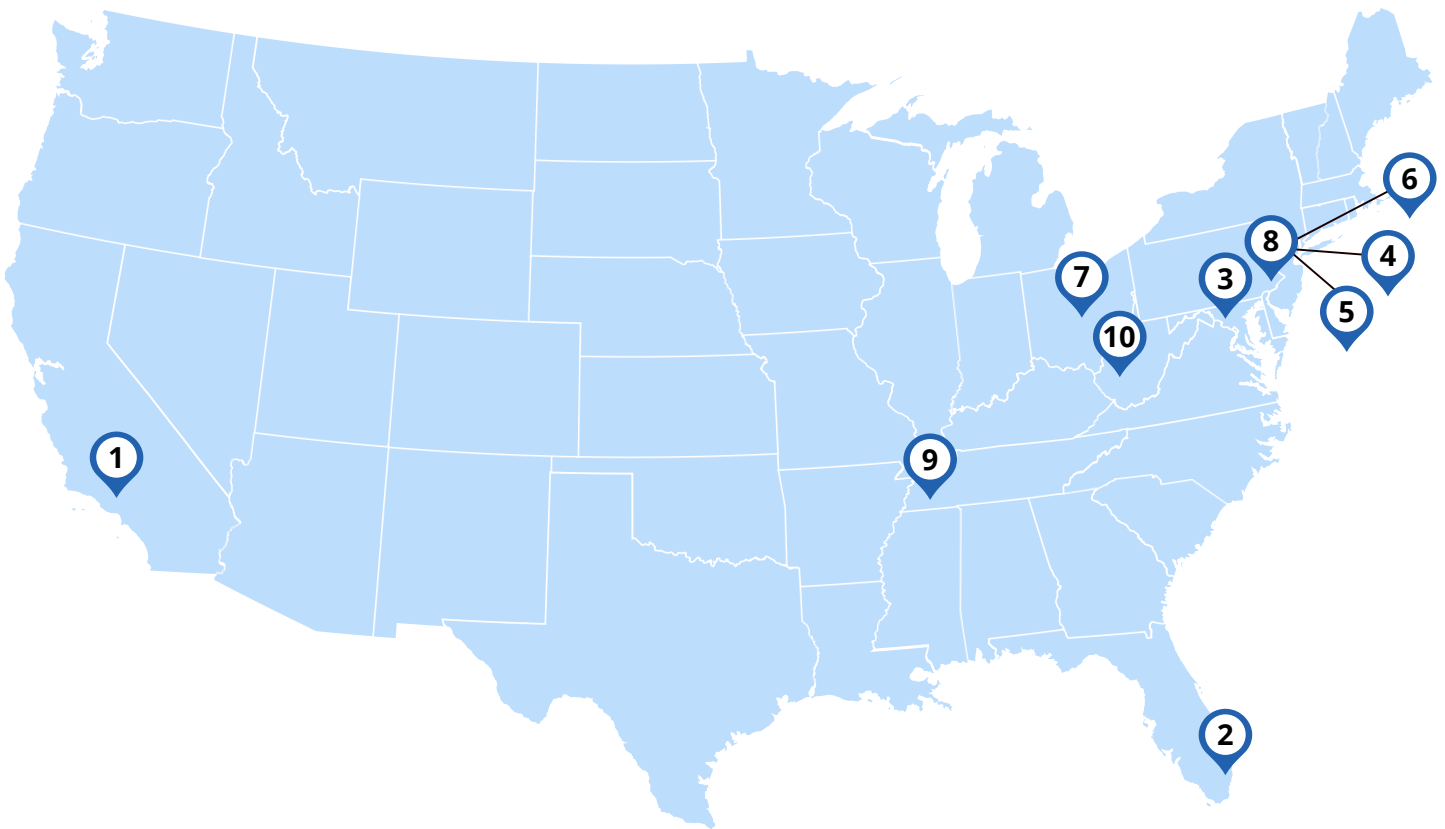
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## DEDICATED TO MAKING A DIFFERENCE

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### Specialty Pharmacies



1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Glen Rock, New Jersey
5. Totowa, New Jersey

6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania
9. Bartlett, Tennessee
10. Charleston, West Virginia

