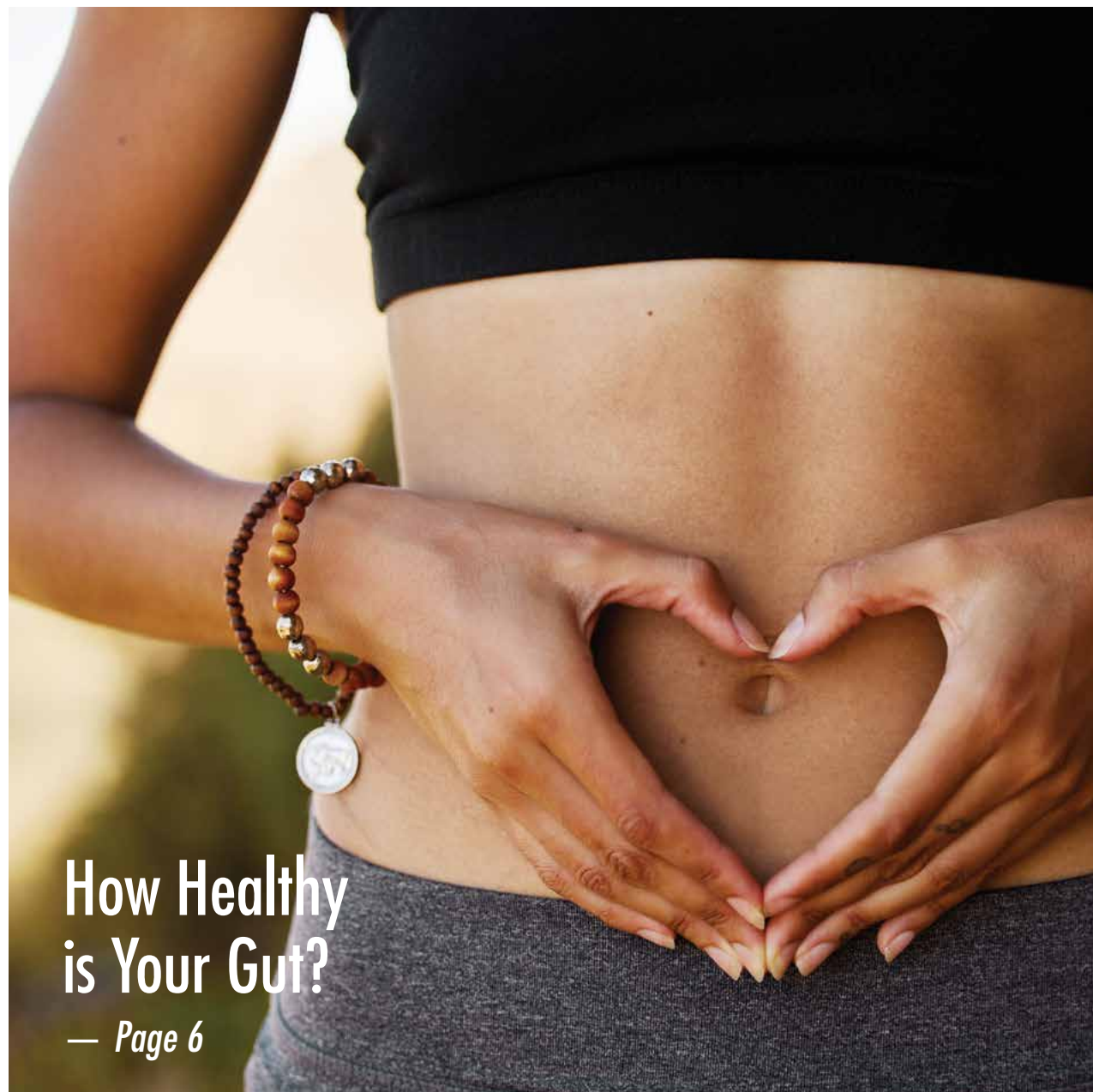


# INFUSING

BONDED BY BLOOD | FALL 2022



How Healthy  
is Your Gut?

— Page 6

TikTok, the  
Pros and Cons

Managing Fear and Pain  
in Kids During Infusions

How Healthy  
is your Gut?

# Specialty Pharmacy 340 (B) PROGRAM



## Welcome to Brothers Healthcare 340 (B) Program

Our dedicated care team *specializes* in supporting the bleeding disorders community.

**Brothers Specialty Pharmacy** care model includes:

- Assist with high-needs patients; responsive communication, social work and nursing coordination.
- Convenient single point of contact for patients' pharmacy needs.
- Working as an extension of your team, our program will increase the operational efficiency of your staff.
- Secure and documented Inventory management system to support audit requirements.
- Program promotion at local and national events.



## We're here to help

We look forward to scheduling a consultation with you to discuss how Brothers Healthcare can better serve you and your pharmacy program.

**Ian Corona**

*Director of Sales & 340 (B) Programs*

**(775) 741-0004**

**[ian@brothershealthcare.com](mailto:ian@brothershealthcare.com)**



Please call us to discuss how Brothers Healthcare can support your 340 (B) growth plans.

[BROTHERSHEALTHCARE.COM](http://BROTHERSHEALTHCARE.COM)

## FROM THE EDITOR

# How can it be?! The end of the year is upon us already!



*Stay healthy and safe,*  
—Kelle Carthey, RN  
Editor

**Brothers Healthcare is back in full swing!** In the last quarter, we are grateful to have joined the community at so many events nationwide, including the NHF Bleeding Disorders Conference in Huston, Texas, and at Familia De Sangre in Anaheim, CA! It was great to see (and hug!!) so many friendly faces! We love that we are back in person, in the community, supporting our friends and family, and staying current with the latest education and therapies available to our community.

As we look forward to 2023, we do so with excitement! Our plans are expanding into reality, our team is growing, our pharmacy is thriving, and the promise of a great year is real! We look forward to continuing to serve your needs and seeing you all at the community events! 🌊



INFUSING LIFE  
FALL 2022

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## ASK US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

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TO KEEP UP WITH THE LATEST  
UPDATES ON OUR EVENTS,  
PROGRAMS AND ACTIVITIES.



MANAGING

# FEAR & PAIN

in KIDS DURING INFUSION

**N**obody enjoys the poke of a needle. As adults, we understand the reason for the procedure, so we grin and bear it. But unfortunately, the anxiety and fear of receiving an injection can overwhelm children.

Children with hemophilia often receive multiple infusions or injections monthly or weekly. Unfortunately, these regular procedures can become a nightmare for patients and caregivers.

Following are several simple steps caregivers can take to minimize the fear and discomfort associated with a child receiving an infusion.

## PREP FOR SUCCESS

Before the infusion, make sure they are well hydrated and bathed. There are several important reasons why.

First, good hydration makes veins plumper. Plumper veins are more prominent and easier to locate, taking the guesswork out of finding and hitting the vein. Less time in preparation reduces the time in anticipation of the poke and helps keep anxiety and fear in check.

Second, a warm bath or shower helps keep the skin warm and pliable. More supple soft skin makes administering an infusion easier. Additionally, warm water helps dilate the veins.

## CREATE A COMFORTABLE ENVIRONMENT

The caregiver must maintain a calm and reassuring disposition. This could easily be one of the best tips we can offer! Children are incredibly adept at sensing emotions. Therefore, speaking in a relaxed, assured tone while keeping your anxious feelings at bay helps set the patient's mind at ease.

The setting where an infusion occurs can make a big difference in a procedure's outcome. Consider a stark, sterile room lit with fluorescent lights. It can feel uncomfortable or even hostile to a scared child.



Instead, the room where a child is treated should be warm and nurturing. Lighting and comfortable furniture create a sense of well-being and safety.

## USE GENTLE LANGUAGE

A caregiver's words when helping a child can lead to different results. Avoid harsh words, like pain or burning. Instead, use language that conveys milder discomfort. For example, as the needle is inserted, it will "pinch a little." As the infusion is taking place, reassurance to the child that they are doing a great job remaining still and checking in with the child's feelings are an excellent way for the child to feel they are successful and have a voice.

The goal is to be honest with the child while describing the procedure in a way that doesn't generate greater fear and anxiety.

## EMPLOY DISTRACTIONS

A child patient can become hyper-focused on an infusion. This fixation heightens the negative emotions associated with the procedure. To alleviate this, caregivers should bring comforting items that can help distract the child.

Unlike a simple injection, an infusion takes a substantial amount of time. The sensations experienced during infusion can be unpleasant and uncomfortable for some. Using distraction to shift the patient's attention away from the process can help them endure it better. A kid's favorite book or toy can help them focus on something other than what is happening. A smartphone playing music or funny videos can also be a terrific distraction for the young patient.

At the time of infusion, encourage the child to look away and utilize distractions to keep the kid's attention focused on anything but the procedure.

## EMPOWER THE CHILD

As adults, we can accept and endure uncomfortable procedures because we know the

long-term benefits of short-term discomfort. But on the other hand, kids may not understand precisely why they are getting an infusion. All they know is that it's painful and scary and that they don't like it.

Explaining the reasons for the procedure can be helpful, but very young patients may not be able to understand. Allowing the child to feel like they have physical control over some processes can lead to more positive outcomes. For example, asking your child to help set up and prep for their infusion can accomplish two things. One, it helps them have a sense of control of the environment, and two, it helps them learn about and grow through what they are going through. Control can help bring peace.

## MINDFULNESS, BREATHING, AND THE POWER OF SUGGESTION

It's important to calm a young patient before they have to undergo an infusion. On a scale of 1 to 10, ask them what their anxiety level is. If it's high, make sure to work on calming them before going forward with the procedure. This can take a lot of practice for some. It's important to remember that infusion of factor products is not up for negotiation. That said, we can offer some control to the child by asking where and when they would like the infusion to occur.

Deep breathing is a simple and effective method of reducing anxiety. Before a procedure, have the patient take several slow, deep breaths. This practice of extending the time of inhalation and exhalation lessens the body's reaction to pain. Breathing with the child to slow down their breathing pace is beneficial, as is employing devices, for example, bubbles or a pinwheel, to extend breath. Slowing a child's breathing down before administering an infusion helps them to remain calm and still.

Visualization is a technique commonly utilized by everyone

from athletes, to actors, to surgeons to increase performance and reduce stress. Playing out a process before undertaking it helps bolster confidence and increases the chances for a successful outcome. It's no different for a kid about to undergo a medical procedure. Helping the child to walk through a successful upcoming infusion in their mind gives them a greater sense of understanding and confidence.

In addition, having them visualize each step in detail — bringing out the medicine, applying the tourniquet around the arm, disinfecting the injection site, etc. — helps to lessen the anxiety that all that put together generates in a young patient.

## THE POWER OF SUGGESTION AND THE "MAGIC GLOVE"

The power of suggestion is another powerful tool for managing perceived pain in young patients. Simple phrases like "you will know what's happening, but you won't be bothered by the procedure" set the child's mind up for a positive outcome.

The "Magic Glove" technique is an example of mild hypnosis used to help a young patient better deal with the discomfort of injection or infusion. The process involves using reassuring language and visualization as the caregiver takes a glove out of their pocket and puts it on the child's relaxed hand. Next, a suggestion is used to make the child feel like the glove on the arm receiving the injection protects them from the procedure's pain. Once the kid is convinced that the "magic glove" is doing what it is meant to do, the injection becomes manageable.

## PHYSICAL NUMBING AGENTS AND VIBRATION

Applying a numbing cream or spray to the skin before inserting the needle for an infusion will help reduce the poke's pain. As

*Continued on page 12*

# Quick TIP

**Doing infusion on yourself or your child can be tricky! Here are a couple "quick tips" for a successful infusion.**



- **Gravity is your friend** — Let the patient's arm dangle down on the side of the bed if no veins are observed to promote venous filling. Gravity slows venous return and distends the veins. Full and distended veins are easier to palpate and are always an excellent option for insertion.

- **Use warm compress** — Apply warm, moist compress or warm towels over the area for several minutes before you insert and, of course, before you cleanse. Leave the compress in place for 10 to 20 minutes. A warmer temperature would enable the vein to dilate and make it more visible to the surface.



## ASK US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

(800) 291-1089  
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# Gut Health

When we think about our health, we think about a variety of factors: Is our weight down? Is our skin adequately protected? Do we get our teeth checked regularly? Here's one you may not have thought about: **How healthy is your gut?**



Believe it or not, maintaining your gut health is one of the most important things you can do for your overall well-being. Let's take a look at why this is the case and how.

## What Is Gut Health?

First, and maybe most importantly, you're probably wondering, "What the heck is gut health?"

Digestion or an upset stomach is typically what comes to mind when most people think of gut health. There's some truth to that. Gut health can impact your digestion levels and how much you weigh. However, good gut health is so much more than that.

Gut health refers to how food is broken down, absorbed into your body, and ultimately turned into "fuel." This fuel is used to power your bodily functions and brain processes. As you likely already know, all food travels a long way in your body to be turned into the nutrients that make your body and brain work. Gut health refers to how all of these processes work together. Your body is a machine, and gut health is no different. If one part is out of balance or breaks down, you could have a significant physical or emotional problem.

Gut health refers to the entire digestive process, including when food enters your body, travels into your stomach, is digested, and absorbed. This is done by a variety of different organs and microbiome bacteria. One of the formerly under-discussed ways in which gut health works pertains directly to the delicate balance of microbiome bacteria and how this specific type of bacteria alters the breakdown and digestion of food.

## The Importance of Gut Microbiome Bacteria

Gut microbiome bacteria is the specific collection of bacteria that lives inside your stomach. These bacteria serve many roles, including:

- Helps break down, digest, and absorb food.
- Ensures vital biological functions operate properly, like maintaining healthy blood sugar and an appropriately functioning immune system.
- Maintains an appropriate weight, as an imbalance of gut bacteria can lead to significant weight problems, high cholesterol, or more.
- Involves the regulation and production of hormones that can have a substantial impact on mental health.

Many different bacteria, yeasts, and other organisms make up gut microbiome bacteria. All of these lifeforms have different functions within your body.

Remember that this bacteria is actually "alive" within your stomach. It operates independently of the rest of your body but typically works in a way that benefits you and the bacteria itself. As such, it's considered a symbiotic relationship in which both organisms benefit from each other.

It's worth examining some of the impacts of gut health in greater detail to understand just how impactful it can be.

## Gut Health and Weight Loss

The types of bacteria that live in your gut are incredibly complex, containing 250-800 times more genetic material than that found in humans. Multiple studies have confirmed that gut bacteria can break down food and ensure that food not absorbed into your bloodstream for nutritional purposes is eliminated from your body.

Different types of gut bacteria work to accomplish this task. However, the opposite is also true. If you have the wrong gut bacteria, your body can store more food, resulting in weight gain.

The study of gut health is still evolving, and there are still many things unknown about the role that bacteria in your gut plays in

terms of weight loss. However, the evidence seems clear that it does play a role and that certain kinds of bacteria can be beneficial for maintaining the right weight and losing weight.

## Gut Health and Mental Health

Gut bacteria and weight loss make intuitive sense. After all, gut bacteria live in your stomach. However, scientists are just starting to explore the interactions between gut health and other areas. A surprising connection has emerged, as some evidence suggests gut health and mental health/overall wellness are connected.

How can this be? Gut health seems to influence the levels of inflammation found in your brain. Brain inflammation has been tied to various negative psychological symptoms, including depression and anxiety. It follows that gut bacteria influence depression and anxiety. It's also worth noting that many connections have been found between digestive problems and mental health.

There seems to be a two-way street. Mental illness can damage gut health, but changes in gut health can also damage your mental health. There's also a clear connection between stress and digestive problems. Therefore, maintaining proper gut health can reduce stress and mental illness.

## How Can I Maintain Gut Health?

Maintaining gut health isn't always a simple experience. On the one hand, there are some obvious answers. Diet and exercise can be very beneficial for your gut. You should speak with a medical professional for more



specific, customized advice on eating right and the right exercise program for you.

However, there are other things you can do to improve gut bacteria and maintain your gut health, including:

- Eat a variety of foods, and don't overeat from one food group. Doing so can ensure that you get the right array of bacteria into your stomach.
- Eat adequate levels of specific foods, including fruits, vegetables, yogurt, legumes, fermented food, and prebiotics.
- Increase the number of probiotics you take. This increase can come in either food or supplements.
- Limit alcohol intake, which can cause stomach problems, and do what you can to reduce your stress levels.

As you can see, gut health is about so much more than just digesting food: It maintains a slew of critical functions for your overall wellness. As such, you should do whatever you can to keep your gut health optimized. 🍌





# TikTok



## What is TikTok Anyway?

The interwebs are ever-changing. As we age, we still think Facebook is cool. By the time you finish reading this article, TikTok may be outdated.

TikTok is a free social media app that anyone can access if they know how to. The app allows users to watch short, choppy videos that can be informational or purely entertaining. You can also use TikTok to create, edit, and share your own videos.

## Who Uses TikTok?

TikTok is what's hip, what's in, what's cool. There are more than 800 million users around the world and it's available in 75 different languages.

TikTok is very popular with the "youngins." But many content makers of all ages upload (that's a fancy word for "put on the app") videos to appeal to the younger crowd. There are videos done by doctors, scientists, business people, and celebrities.

## TikTok's User Age Guidelines

Let's keep our kids safe and age-appropriate. When setting up TikTok for your kid, make sure the age is set up correctly so the features reflect how to keep them safe. Below is a chart made to simplify the confusion.

Age	Only Age Appropriate Content	Make Videos or Comment	Search for Videos	Friends Comment on their Content	Direct Messaging	Live Stream
Under 13	X					
13 - 15		X	X	X		
16 - 17		X	X	X	X	X



## What Can You Watch on TikTok?

If you don't enjoy dancing videos or people lipsyncing, chances are you've never watched TikTok. But TikTok has branched out in the type of content that's offered.

Users can create short videos on just about anything. Think of it as Youtube for people with attention issues.

## Some of the most popular video categories include:

- Entertainment
- Pranks
- Sports and fitness
- Home renovations and DIY
- Beauty and skincare
- Fashion
- Recipes and cooking
- Advice and life hacks
- Pets
- Outdoors

## Learn Something New on TikTok

This goes beyond just entertainment. There are a lot of things that you can learn from watching TikTok videos, pointless or otherwise. Many professionals share their knowledge through the app. This includes:

- Scientists
- Teachers
- Doctors
- Dermatologists
- Financial advisors
- Voice coaches
- Journalists
- Dieticians

There are tips and tricks for so many topics that may advance your trivia knowledge. You do need to be careful though.

Anyone using TikTok for learning should make sure the video is done by an actual professional. And even if it is done by a professional, let's be honest — what are they trying to sell?

## The Pros and Cons of TikTok

You mean to tell me TikTok isn't all rainbows and sunshine?

## The Pros

TikTok can be a good form of entertainment for really anyone. There are plenty of options of videos to choose from. TikTok has lots of dance videos, lip syncing, duets, and comedy sketches for people to enjoy.

It can be a good way to connect with people. TikTok is a social network (which means networking through the interwebs). People can add encouraging comments to others' videos and build digital relationships.

The ways of snail mail are dying. Sorry, United State Postal Service. You can DM (direct message) back and forth through TikTok.

Making TikTok videos is a way to express yourself creatively. It doesn't take a lot of equipment to make the videos and share them; people can just use their phones.

TikTok can provide instant publicity for people who want to become well known. This can be professionally or personally. Some TikTok users have become famous without having a specific gift, talent, or skill. You can literally be famous for nothing.

Again, TikTok can be a place to learn new things. Just make sure the source is credible.

You can become a paid content creator if you're popular enough. When a user gets enough followers and video views they can start making money. To get paid, you need to have at least 10,000 followers on the app.

Once you have 100,000 video views in the last thirty days you can apply for the TikTok creators fund. Not many people make it this big, but it is possible.

## The Cons

TikTok can be a big time-waster. Like Facebook, TikTok has no end. So infinite scrolling addiction can occur. Setting a time limit through your phone or secondary safety app can help with this problem.

Whenever people are involved, negativity can spread, regardless of the platform. Unfortunately, TikTok is no

different. Some people use this social media platform to tear others down and discourage them. People have used TikTok to make fun of certain people groups or to make others look bad in public.

Educating our children on how to respond to negativity and discouraging comments is really important. Negative comments on videos can impact self-esteem and reduce self-confidence. The more a person shares videos, the more likely someone will have a negative comment to add. This can be especially hard on children and teens.

Regardless of the safety settings in place in TikTok or any other app, there is also the risk of inappropriate content being available to children. There's a reason there's a "report" option on content. Not everything can be caught by TikTok. We need to be our own advocates when allowing our kids access to apps.

## Keeping Children and Teens Safe While Using TikTok

As parents, grandparents, and caregivers we have a responsibility to our kids to keep them safe while helping them navigate the changing world of communication. We can teach children and teens how to stay safe online, on any social media platform. We can educate ourselves and them about the potential dangers of social media.

Do you know who they have access to? Have conversations about adding people that they do not know on their social media accounts. Children and teens need to understand that there are some people out there who do not have their best interests at heart.

Keep an eye on the content they're watching. Even if you have settings in place, your values may not line up with what TikTok thinks is appropriate for your kiddos. It is a good idea to check what videos they are watching to make sure the content is appropriate.

“TikTok is what's hip, what's in, what's cool. There are more than 800 million users around the world and it's available in 75 different languages.”

Peer and popularity are still true for kids of our generation and the current one. Trying to outdo one another or following suit with silly or dangerous challenges being posted is a real thing.

**Viral challenges are just one example of why we need to be aware of what our kids are watching and posting:**

- **Gallon Challenge** - Chugging a gallon of milk without vomiting
- **Cinnamon Challenge** - Eating a spoonful of cinnamon without a drink
- **Salt and Ice Challenge** - Placing salt on your arm and then adding ice to the area, causing frostbite burns
- **Tide Pod Challenge** - Eating tide pods

## The Bottom Line

There are many reasons to be on TikTok or other social media that are beneficial and entertaining. Knowing how to talk to our kids and set up boundaries of what is appropriate is key. We can use social media for great things, but common sense needs to be taught first.

When used the right way, TikTok can be a lot of fun. Your family might even want to try making some TikToks together! You never know when a viral idea will hit. But in the meantime, keep it light, and above all, enjoy the amusing parts of this great app. 🌈

NOW APPROVED FOR ONCE-WEEKLY PROPHYLAXIS

# BE READY FOR THE UNEXPECTED

ONCE-WEEKLY REBINYN® HELPS YOU KEEP FACTOR 9 LEVELS HIGHER FOR LONGER<sup>a</sup>

Timothy has severe hemophilia B and uses Rebinyn®.

Expect higher factor levels and bleed protection with once-weekly Rebinyn®.<sup>b</sup>



With once-weekly Rebinyn®, adults and adolescents with hemophilia B can spend approximately 80% of their week with Factor 9 levels in the non-hemophilia range (greater than 40%).<sup>b</sup>



in adults treated with Rebinyn® 40 IU/kg<sup>c</sup>



in adolescents treated with Rebinyn® 40 IU/kg<sup>c</sup>

Visit [www.rebinyn.com](http://www.rebinyn.com) to learn more about once-weekly Rebinyn®

<sup>a</sup>Rebinyn® achieved and maintained higher factor levels than recombinant Factor 9 based upon a phase 1 study comparing 25, 50, and 100 IU/kg doses of Rebinyn® to a 50 IU/kg dose of standard half-life recombinant Factor 9 in 7 adults and a 50 IU/kg dose of plasma-derived Factor 9 in 8 adults. For Rebinyn®, estimated average Factor 9 activity is adjusted to a dose of 50 IU/kg. Incremental recovery at 30 minutes (IR<sub>30</sub>) and half-life were higher and longer with Rebinyn® than recombinant Factor 9 (IR<sub>30</sub> 0.0131 vs 0.0068 (IU/mL)/(IU/kg) and half-life 93 vs 19 hours). The clinical relevance of these pharmacokinetic differences is unknown.

Incremental Recovery: The increase in plasma concentration per IU/kg of factor administered.

Half-life: The time it takes for the level of factor in the blood to fall by half (50%).

<sup>b</sup>Data represent mean steady-state pharmacokinetic (PK) profiles from previously treated adolescent/adult patients with moderate-to-severe hemophilia B (N=9) taking repeated doses of Rebinyn® 40 IU/kg once weekly. Factor 9 levels were within the non-hemophilia range (greater than 40%) for 5.4 days (about 80% of the week).

<sup>c</sup>Based on analysis using a 1-stage assay in patients (N=6) aged 18 and older, the half-life at steady state was 115 hours following once-weekly (40 IU/kg) dosing; in patients (N=3) aged 13 to 17, the half-life at steady state was 103 hours. Following single-dose administration (40 IU/kg) in the same patient population, the half-life was 83 hours (adults) and 89 hours (adolescents).

## Indications and Usage

### What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for immune tolerance therapy.

## Important Safety Information

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

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

### Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

### What should I tell my healthcare provider before using Rebinyn®?

Tell your healthcare provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

### How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.
- Do not stop using Rebinyn® without consulting your healthcare provider.

### What are the possible side effects of Rebinyn®?

- Common side effects include infusion site reaction (bruising, bleeding, swelling, pain, or redness), itching, and rash.
- Your body can also make antibodies called "inhibitors" against Factor IX, including Rebinyn®, which may stop Rebinyn® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Call your healthcare provider right away or get emergency treatment right away if you get, for example, any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness, or swelling.
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) in certain cells in the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

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.



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**rebinyn®**  
Coagulation Factor IX  
(Recombinant), GlycoPEGylated

# rebinyn®

## Coagulation Factor IX (Recombinant), GlycoPEGylated

### Brief Summary Information about:

### REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

#### Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/REBINYN.pdf](http://www.novo-pi.com/REBINYN.pdf) to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

### Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill, as there may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

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

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

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

### What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

### Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

### What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing. It is not known if REBINYN® passes into breast milk or if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if REBINYN® may harm your unborn baby.
- Have been told that you have inhibitors to Factor IX (because REBINYN® may not work for you).

### How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

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

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

### **Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.**

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

### Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

### If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and speak to your healthcare provider if you have any questions or concerns.

### If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

### What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

### What are the possible side effects of REBINYN®?

#### **Common Side Effects Include:**

- infusion site reaction (bruising, bleeding, swelling, pain, or redness)
- itching
- rash

Your body can also make antibodies called "inhibitors" against Factor IX, including REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get, for example, any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

### What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

### How should I store REBINYN®?

**Prior to Reconstitution** (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

### After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

### What else should I know about REBINYN® and hemophilia B?

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

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 07/2022

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: <http://novonordisk-us.com/patients/products/product-patents.html>

Manufactured by:  
Novo Nordisk A/S  
Novo Allé, DK-2880 Bagsværd, Denmark

**More detailed information is available upon request.**

Available by prescription only.

For information about REBINYN® contact:  
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the child realizes the pain isn't all that bad, they become MUCH less anxious about getting the infusion. It's safe to say these creams/patches and sprays will not remove the poke's pain altogether but will decrease it significantly, to the point they may not care.

There are several numbing products on the market. One of our favorites is called Synera. Synera looks like a large band-aid but has numbing medicine in the center. Synera is available with a prescription from your doctor. Other products like **lidocaine 4% cream are available over the counter at drug stores and on amazon.com, etc. Either option will take 30-60 minutes before they work thoroughly- so apply with enough time before the anticipated procedure.**

Additionally, mild vibration has been shown to reduce pain. While there are medical vibrators explicitly manufactured for this




purpose, any home vibrating massager can be used to massage the injection site and reduce discomfort.

### INCENTIVIZE

Help the young patient to see beyond the infusion by giving them something to look forward to after it's over. Use their fa-

vorite activities as rewards. The promise of an hour at the park, eating a savory treat, or watching a treasured movie helps the patient make positive associations with an otherwise negative experience. Knowing something good is waiting for them on the other side of the infusion helps give them something to look forward to.

Nothing is fun about an infusion, but incorporating pre, during, and post-procedure strategies into the caregiving routine can help a young patient feel more in control and less fearful. Less anxiety from a child undergoing an infusion makes everyone's experience, from caregiver to doctor to patient, less frustrating and more positive. 



**Saturday 1:22 pm**  
Swinging in the  
backyard with mom  
Evan, living with  
hemophilia A

Not an actual patient

## WE'RE IN THIS TOGETHER.

### Let's make today brilliant.

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

[bleedingdisorders.com](https://bleedingdisorders.com)



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