

# NAVIGATING INDEPENDENCE

while managing your treatment for hemophilia B



## Congratulations!

You're beginning a new phase of your life. Whether you're attending college, moving to a new home, starting a new job, or simply doing more things on your own, it's an exciting time. It's also an important moment for thinking through what's ahead, especially when it comes to keeping up with your hemophilia B treatment. This guide is designed to help you build habits to manage your care and health as you take on new exciting challenges and responsibilities.

In this guide, we'll cover 3 key areas to consider as you prepare for being more independent:



### Your relationship with yourself

It all starts with you. If you've been living at home and relying on others to help you manage your hemophilia B, the transition to independence takes strength—and belief in yourself. You've got this!



### Your relationship with your support network

Whether you're transitioning to a new healthcare network, learning about insurance coverage, or simply adjusting to a different routine, your team is behind you. An important part of this transition is learning how to communicate with everyone on your care team, including your doctor, their staff, and your parents or caregivers.



### Your relationship with others

No matter what stage of life you're going through, building and maintaining a healthy social network is important. We'll talk about how you can make meaningful connections to help you feel supported, confident, and comfortable.

Please see full [prescribing information](#) for IDELVION, including patient product information, and [Important Safety Information](#) on [page 5](#).



Your relationship with

# yourself



## Learn

### Why self-efficacy matters

It's not just about doing it—it's about believing you can do it. In psychology, "self-efficacy" refers to the belief that you can accomplish a task or goal. People who have higher self-efficacy for certain tasks, like taking medication on time or communicating with their support network, tend to have more success managing their condition, even through big life changes.



## Think

### Reflect on what you've already accomplished

Your routine has changed in the past. For example, did you learn how to ride a bike or manage your own bank account? When you think about it, you've tried lots of new things in your life.

**Did someone help you make the change?** For example, did you have someone you could go to when you needed help? Or, if you experienced a loss or a big disappointment, how did you get back on track?

**Focus on how it felt when you succeeded.** To get this far, you've already faced challenges—and adapted. Remember that sense of accomplishment, and remind yourself that you can achieve new goals in the same way.



## Act

### Building your self-efficacy

**Make a plan using IF-THEN statements.** Prepare for future situations with IF-THEN statements by making clear plans, anticipating your next steps, or deciding how you will respond to challenges. For example:

“ **IF** I feel uncertain about an activity that could cause a bleed, **THEN** I'll send a text message to my care team to ask for advice. ”

“ **IF** I have a lot of travel coming up, **THEN** I'll ask my healthcare team about moving to a 14-day dosing schedule to extend the time between my infusions. ”

“ **IF** I'm unsure about participating in an activity, **THEN** I can ask my healthcare team to check my Factor IX levels and adjust my dose to ensure I'm protected from bleeds. ”

**Write it down.** If you're facing a situation where you're feeling uneasy, think of a good friend and imagine the encouraging things they'd say. Then write that down.

**Set regular reminders.** When you stay on track with your treatment, you can be confident that IDELVION can keep you protected from spontaneous bleeds.<sup>†</sup> Use a reminder app on your phone to keep track of infusions and other responsibilities, like your next study group meetup or clocking in and out of work.



Please see full **prescribing information** for IDELVION, including patient product information, and **Important Safety Information** on page 5.



Your relationship with

# your support network



## Learn

### Communication is key

Keep your support network updated on your new setting. Your caregivers have been involved in your care from the start, and they understand your unique needs best. As your advocates, they will continue to be assets to you as you adapt to managing hemophilia B on your own. It's a lot to take on, so don't forget they are still part of your care team and will be there to offer support and advice.



## Think

### Make a mental inventory

What parts of your treatment plan will you be in charge of now? Imagine you are explaining each step of your treatment process to someone new: how to store your treatment, schedule appointments, manage insurance, and navigate coverage.

**Who helped you manage your treatment in the past?** As you build a list of the things you'll be responsible for from now on, don't forget to ask the experts: your parents or caregivers.

**How will your dosing schedule fit your new routine?** Remember, with IDELVION, you can have flexibility with 7- or 14-day dosing, depending on your age. If you'd like to talk about adjusting your dosing schedule to have more time between infusions, reach out to your care team.



## Act

### Create a plan, share the plan

1. Decide how and where to store your hemophilia B therapy and supplies, especially if you're living in a shared space, like a dorm room or apartment.
2. Schedule a monthly call with your parents or caregiver to talk about treatment, including insurance coverage and finances.
3. Have a conversation with your healthcare team to talk about your new life change or transition. Make sure to share your insurance information with your care team so you can schedule visits when needed and keep up with treatment.
4. Sign up for IDELVION Connect<sup>SM</sup> to get personalized one-on-one services and access to a range of resources, including insurance assistance and copay support.

### KNOW YOUR FACTOR IX LEVELS

Do you know what your Factor IX levels are and the half-life of your treatment? Keeping these in mind can help you know when you're best protected from bleeds. In adolescents and adults, IDELVION delivers **20% steady-state trough levels with 7-day prophylactic use.<sup>†</sup>**

Please see full **prescribing information** for IDELVION, including patient product information, and **Important Safety Information** on page 5.

IDELVION DELIVERS

**7 and 14 DAY DOSING FLEXIBILITY<sup>§</sup>**  
FDA-APPROVED FOR ADOLESCENTS AND ADULTS



# Your relationship with **others**



## Learn

### Making meaningful new connections

**Find people who get you.** When you're moving away from home, you may meet new people and make new friends with your peers. Living with hemophilia B can add an extra layer of complexity. Who do you decide to tell? Who can you trust to ask for help or support? Take a moment to consider the kinds of friendships you want to build—and how to build them.



## Think

### What do you look for in a friend?

Consider your own identity

How do you see hemophilia B as part of who you are?

Recall what you have shared in the past

How did you tell the friends you have now about living with hemophilia B? How did it go? Was it as big of a deal as you thought? How have your friends and family helped you manage your hemophilia B in the past?

Identify how others have offered support

What qualities do you look for in a supportive friend? What do you want to make sure your support network knows about you?



## Act

### Start the conversation with confidence

1. First, consider who needs to know about your condition (Example: your care team, closest friends, your employer).
2. Start by sharing with people you trust (Example: a roommate, close friend, or a significant other).
3. Then, think about when or where you want to share (Example: in a private 1:1 setting).
4. When you're ready, ask permission to share. Here's an example of what you could say:

“ Is it okay if I share something about my health with you? I have a condition called hemophilia B. ”

Don't forget to talk about the role of treatment. For example:

“ I get infusions of a medication called IDELVION. It helps keep me protected from bleeds with high trough levels, which is why it's important for me to stay on track with treatment. ”

Please see full **prescribing information** for IDELVION, including patient product information, and **Important Safety Information** on page 5.

IDELVION DELIVERS  
**20%** STEADY-STATE  
TROUGH LEVELS  
WITH 7-DAY PROPHYLACTIC USE<sup>4</sup>

## IMPORTANT SAFETY INFORMATION

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

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.

The most common side effects of IDELVION are headache and dizziness. These are not the only side effects possible. Tell your healthcare provider about any side effect that you experience, and contact provider immediately if bleeding does not stop after taking IDELVION.

**Please see full [prescribing information](#) for IDELVION, including patient product information.**

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**.

### SIGN UP FOR IDELVION CONNECT<sup>SM</sup>

Visit [idelvion.com/sign-up](http://idelvion.com/sign-up) to enroll in IDELVION Connect<sup>SM</sup>

### INSURANCE NAVIGATION

When you call **1-800-676-4266**, an IDELVION Connect<sup>SM</sup> Case Manager can determine program eligibility and help answer questions about insurance. Monday–Friday, 8 AM to 8 PM ET

### COPAY SUPPORT PROGRAM

Helps eligible people with commercial insurance by assisting with out-of-pocket expenses for IDELVION

### ASSURANCE

The Assurance program can help eligible patients continue to receive treatment even if they experience a lapse in third-party private health insurance

### STRENGTH IN COMMUNITY



Scan this QR code for additional helpful information about hemophilia B as well as links to several local and regional patient organizations that can also be a source of support

## CSL Behring

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC.

IDELVION<sup>®</sup> is a registered trademark of CSL Behring Lengnau AG.

IDELVION Connect<sup>SM</sup> is a service mark of CSL Behring LLC.

©2024 CSL Behring LLC. 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA