SDM

WFH SHARED DECISION MAKING TOOL

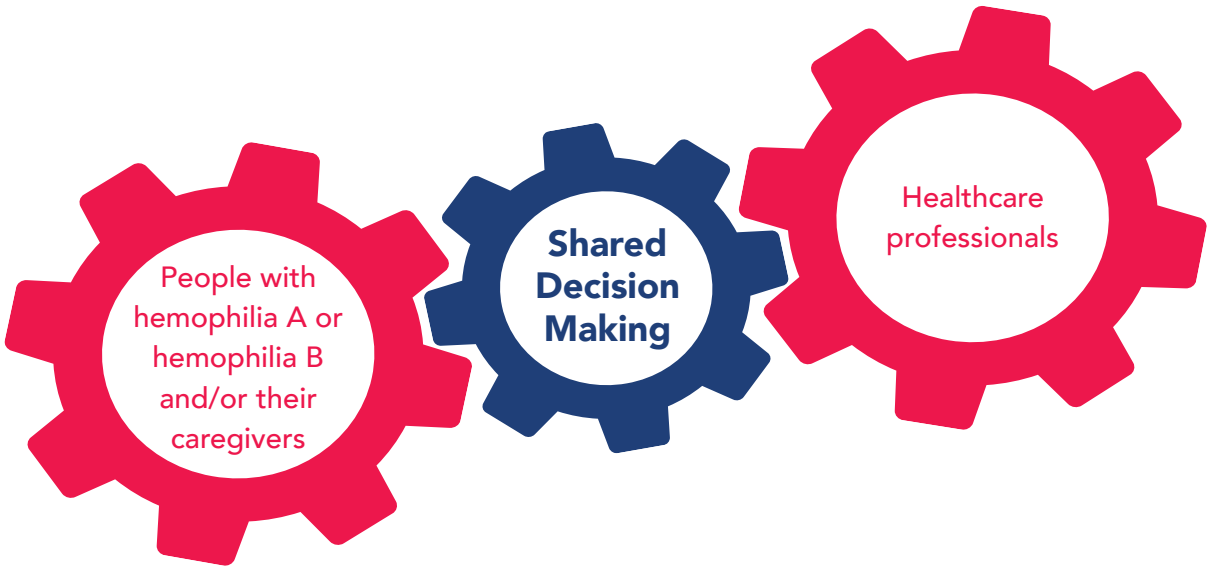
The WFH Shared Decision Making Tool and Workbook: Shared Decision-Making in Hemophilia Management and Care

When people with hemophilia and clinicians make decisions together

WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

Hemophilia Management and Care: The WFH Shared Decision-Making Tool



The WFH Shared Decision Making (SDM) Tool and Workbook are for people with hemophilia A or B and their healthcare team. It defines the best practice for shared decision-making in hemophilia treatment and care, and provides a guide for people with hemophilia, caregivers, and healthcare professionals to facilitate successful shared decision-making.

The online WFH SDM Tool and the interactive Workbook were developed by a collaborative and diverse working group of people with hemophilia, physicians, advocates, and other stakeholders with experience in hemophilia treatment, management, and care. Development was led by the World Federation of Hemophilia and funded by BioMarin Pharmaceutical Inc., CSL Behring, Novo Nordisk, Pfizer, and Spark Therapeutics.

This workbook does not constitute medical advice. The content offered herein is intended to educate people with hemophilia, their caregivers, and healthcare teams on treatments for hemophilia. Nothing should be considered or used as a substitute for medical advice, diagnosis, or treatment. You should always talk to your healthcare provider for diagnosis and treatment, including your specific medical needs. None of the education and information offered through this Workbook represents or warrants that any product is safe, appropriate, or effective for you. We advise users to seek the advice of a physician or other qualified healthcare provider with any questions regarding personal health or medical conditions.

This is a living document that will be updated with new evidence twice per calendar year. The cutoff dates for new data or evidence are July 31 and January 31, with updates taking place in the following months. Any new evidence after these cutoffs will be included in the next update.

Updated March 2025

Contents

A Information About Hemophilia

What is hemophilia?

Hemophilia A and B are genetic or acquired bleeding disorders caused by missing or defective clotting Factor VIII (FVIII or F8) in hemophilia A or Factor IX (FIX or F9) in hemophilia B. The lack of a working clotting factor leads to increased bleeding time. Hemophilia is considered a rare disease, with an estimated global prevalence of approximately 1 in 10,000 people for hemophilia A and 1 in 50,000 people for hemophilia B. With the currently available treatments and proper adherence to treatment, people born today with hemophilia can lead healthy lives and have a normal life expectancy. However, access to adequate treatment varies globally and is sub-optimal in most countries around the world.[1]

Life with hemophilia

People with hemophilia can bleed inside or outside the body. Most bleeding in hemophilia occurs internally, into the muscles or joints. The most common bleeding sites are the ankles, knees, and elbows. The most common muscle bleeds occur in the muscles of the upper arm and forearm, the iliopsoas muscle group (hip flexors), and the thigh and the calf muscles of the legs.[1] Repeated bleeding in the same joint can cause other issues like pain and arthritis.

What are the levels of severity of hemophilia?

There are three levels of severity of hemophilia: mild, moderate, and severe.[1] The level is measured as the percentage of normal factor activity in the blood or in the number of international units (IU) per millilitre (mL) of whole blood. The normal range of clotting factor VIII or IX in the blood is 40% to 150%. People with factor activity levels less than 40% are considered to have hemophilia. In people whose bleeding pattern does not match their baseline factor level, their bleeding symptoms will outweigh their factor levels when considering treatment options.

My factor level is:

_____

Severity	Clotting factor level	Bleeding episodes
Mild hemophilia	5% to < 40% of normal (or 0.05-0.40 IU/mL)	• Might bleed for a long time after surgery, dental extraction or a very bad injury • Rarely bleeds unless injured (rarely has spontaneous bleeding)
Moderate hemophilia	1% to 5% of normal (or 0.01-0.05 IU/mL)	• Might bleed for a long time after surgery, a bad injury, or dental work • Might bleed for no clear reason (occasional spontaneous bleeding)
Severe hemophilia	< 1% of normal (or < 0.01 IU/mL)	• Bleed often into the joints and sometimes the muscles • Can bleed for no obvious reason (spontaneous bleeding)

*Adapted from Table 2-1 of the WFH Guidelines for the Management of Hemophilia, 3rd edition

B Understanding Shared Decision-Making (SDM)

What is SDM?

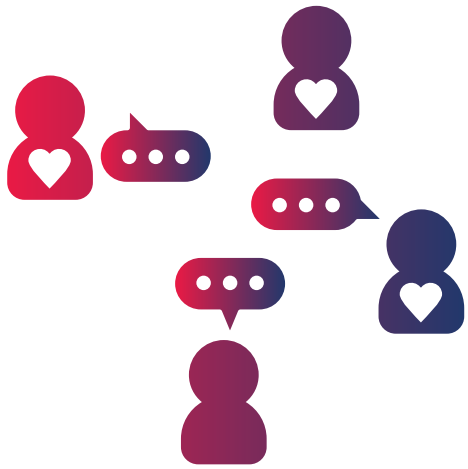
Shared decision-making (SDM) is a collaborative process where you and your healthcare team work together to make a decision about your hemophilia care and treatment.[2] Your decision should be made through thoughtful consideration and discussion around the following:

- Your life goals and how they are affected by your hemophilia
- Your treatment preferences
- The therapies that are available to you
- The available information about each therapy

Why SDM matters

Shared decision-making allows for the relationship between the patient and healthcare team to become a partnership. When patients have equal partnership in their healthcare decisions:

- The patient and healthcare team have a clear understanding of what is important to the other.
- Patients feel more empowered to make informed choices.
- Patients are more engaged in their treatment.
- There is improved treatment adherence, treatment satisfaction, and quality of long-term health care.



The importance of SDM in the management and treatment of hemophilia

The importance of the patient perspective in hemophilia management and treatment has been steadily growing. People with hemophilia are increasingly becoming active members of their own healthcare team, as well as active members of clinical research, medical education and training initiatives. Additionally, the increasing number of treatment options has created a need for ways to individualize and optimize treatment plans so that they align with individual patient preferences.[1] As you embark on the SDM process, remember:

- The care and support you receive should consider your life goals and treatment preferences.
- You have the right to be involved in the discussion and to make decisions about your treatment and care.
- You should feel empowered to clarify issues relating to your treatment.
- It is important that your treatment plan is renewed and revisited regularly, especially as circumstances in your life or treatment options change.

C The SDM Patient Journey: A Step-by-Step Guide

This workbook and the online WFH SDM Tool were designed to guide and support people with hemophilia A or B and their caregivers in gathering information so that they can have more meaningful and collaborative conversations with their healthcare team. You can use this workbook on its own, or together with the online WFH SDM Tool. After using this workbook and talking with your healthcare team, you may decide to remain on your current treatment, modify your current treatment, change to a new treatment, or continue learning about your options. This workbook and the online WFH SDM Tool will be updated as new information and treatments become available.

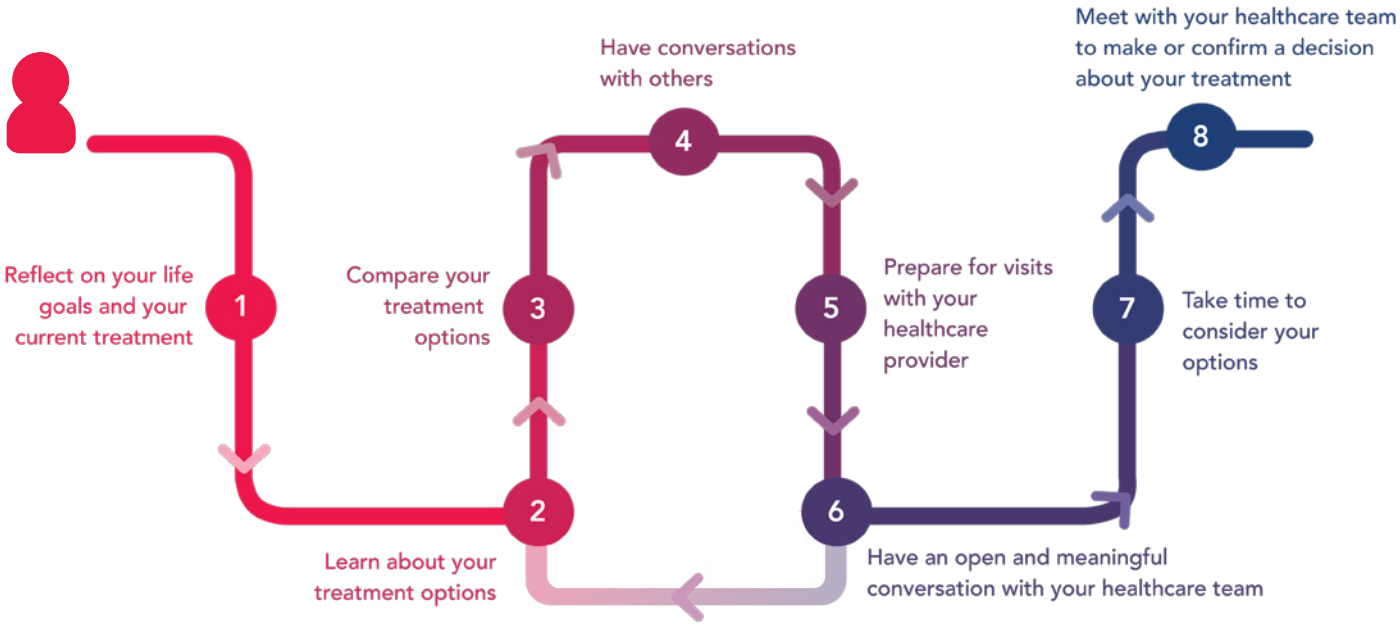
This workbook and the online WFH SDM Tool will help you:

- Take your time to reflect on your life with hemophilia.
- Educate yourself about the available treatment options.
- Come up with questions to discuss with your healthcare team.
- Take notes at your hemophilia treatment center by using the convenient worksheets at the end of this workbook.

To view the online WFH SDM Tool, scan or click below

sdm.wfh.org

This is a simplified example of the SDM Journey. While it is recommended to use SDM when making decisions about your hemophilia management and care, it is also okay to defer to the clinician. However, it is always important that you understand your options and why a particular treatment has been chosen.



Step 1: Reflect on your life goals and your current treatment

When considering a change in your hemophilia treatment, it is important to reflect on your life goals and treatment preferences and how they are impacted by your hemophilia.

1. How would you describe the impact of your hemophilia on obtaining your life goals? (e.g. goals related to work, education, family, hobbies, etc.)

2. What are your treatment preferences? (e.g. frequency, length of time, and method for administration, ease of use, greater efficacy, etc.)

3. Why are you considering a change to your therapy?

4. Is there anything else you want your healthcare team to know about your hemophilia management?

On a scale of 0 to 100, rate how much you agree with the following statements:

1. I feel tied to (or constrained by) my hemophilia treatment regimen.

0 20 40 60 80 100

Not at all Very much

2. Managing my hemophilia takes a lot of effort.

0 20 40 60 80 100

Not at all Very much

3. My hemophilia is always in the back of my mind.

0 20 40 60 80 100

Not at all Very much

4. I feel adequately protected against bleeds.

0 20 40 60 80 100

Not at all Very much

5. I am concerned about the potential side effects of novel therapies for hemophilia.

0 20 40 60 80 100

Not at all Very much

6. I feel upset about missing significant opportunities because of my hemophilia.

0 20 40 60 80 100

Not at all Very much

7. My hemophilia makes it difficult to keep up a satisfying social life.

0 20 40 60 80 100

Not at all Very much

8. My hemophilia keeps me from being able to fulfill the roles I expect to be able to do.

0 20 40 60 80 100

Not at all Very much

- Daily concerns
- Occasional concerns
- Little to no concerns

The Psychosocial Burden of Hemophilia

Hemophilia has a daily impact on the physical and mental life of patients, their caregivers, and loved ones. However, it is difficult to measure the mental impacts of hemophilia. The hemophilia-free mind framework[4] was developed as one way to assess the daily concerns that someone with hemophilia may have regarding the treatment and management of their hemophilia. New treatment advances can move many of these daily concerns into the realm of only occasional concerns and even into areas of little or no concern.

The degree of concern will vary from both person to person and treatment to treatment. Knowing your personal level of concern may be helpful when evaluating which treatment is right for you.

People with hemophilia are encouraged to read and think about their treatment options before an in-depth discussion with their healthcare team. Having a general understanding will help you consider which treatment option is best for you.

Step 2 & 3: Learn about and compare your treatment options

The four main treatment types for prophylactic management of hemophilia are clotting factor replacement therapy, bispecific antibody therapy (hemophilia A only), hemostatic rebalancing therapy, and gene therapy. All these treatments help the blood clot more efficiently, but they all work in different ways and have different safety considerations, risks, and benefits. It is important to understand and consider all these facts when making an informed decision about your hemophilia treatment.

To find more information about these treatments, scan or click below

What is prophylaxis?

Prophylaxis in hemophilia is defined as the regular administration of products aimed at preventing bleeding and maintaining homeostasis. With prophylaxis, people with hemophilia can lead active lives and achieve a quality of life comparable to people without hemophilia.

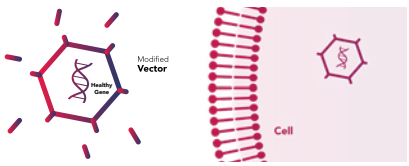
Therefore, the WFH strongly recommends prophylaxis in people with a severe hemophilia phenotype to prevent spontaneous bleeding and joint damage. Prophylaxis regimens should be individualized and according to your symptoms, biological response, and personal preferences.[1]

Clotting Factor Replacement Therapy

Bispecific Antibody Therapy

Hemostatic Rebalancing Therapy

Gene Therapy



Clotting Factor Replacement Therapy

Clotting factor replacement therapies provide the missing FVIII for hemophilia A or FIX for hemophilia B, which allows the blood to clot efficiently.[1,3]

Clotting factor replacement therapies cause a temporary increase in factor levels by providing the needed clotting factor protein; therefore, the effects are temporary, and infusions must be administered regularly to maintain effective clotting factor levels and prevent bleeds (prophylaxis) or as needed to stop ongoing bleeds (on-demand).

The three clotting factor replacement therapy types are standard half-life (SHL), extended half-life (EHL), and ultra-long half-life (UHL; hemophilia A only). Half-life refers to how long it takes for the replacement clotting factor to decrease by half inside your body. There are many different SHL and EHL medications available for both hemophilia A and hemophilia B. After infusing clotting factor replacement therapy, your factor levels increase immediately but decrease over the next few days. EHL products will keep your factor levels higher, for a longer period of time.

The most recent clotting factor replacement therapy for hemophilia A is a UHL that has a 3- to 4-fold longer half-life compared to other FVIII clotting factor replacement therapies and therefore requires less frequent treatment.[3] This longer half-life provides mild-to-normal factor VIII activity between treatments, and therefore, is sometimes referred to as "high sustained factor" (HSF) therapy.

Standard Half-Life

Extended Half-Life

Ultra-Long Half-Life

What is an inhibitor?

One of the most significant side effects associated with clotting factor replacement therapy is the potential development of inhibitors, which are an immune response where the body develops antibodies that can bind to and stop the effects of replacement clotting factors. If inhibitors are going to occur, they typically develop within the first 75 days of exposure. Inhibitors occur in approximately 20–30% of previously untreated people with hemophilia A and in about 3–5% of previously untreated people with hemophilia B.[1] The rate of inhibitor development is unknown for treatment with UHLs.

To learn more about inhibitors, scan or click below

Eligibility

	Approval Status	Year of First Approval	Approved Population
SHL	Multiple products that are widely approved	1993	All ages Some SHL and EHL medications have age restrictions or special considerations for children and infants
EHL	Multiple products that are widely approved	2014	
UHL	Hem A only — One approved product	2023	

Administration

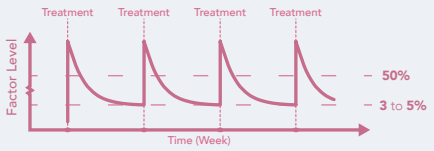
	Administration & Dosing		Location	Yearly Follow-up Schedule
	Hem A	Hem B		
SHL	2-4x/WEEK	1-2x/WEEK	Home or Treatment Center	1-2 Times per year and as needed
EHL	2x/WEEK	1x/WEEK		
UHL	1x/WEEK			

Efficacy

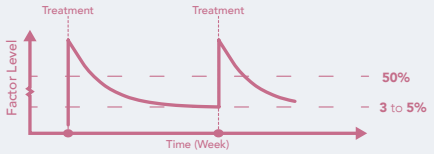
		Median Annual Bleed Rate*	% With Zero Bleeds*	Average Half-life in Adults
SHL	Hem A	0 - 2	38 - 52%	10 - 18 hrs
	Hem B	1 - 2	31 - 43%	23 - 26 hrs
EHL	Hem A	1 - 2	38 - 45%	15 - 22 hrs
	Hem B	1 - 2	not reported	86 - 115 hrs
UHL	Hem A only	0	55%	48 hrs

Factor Level

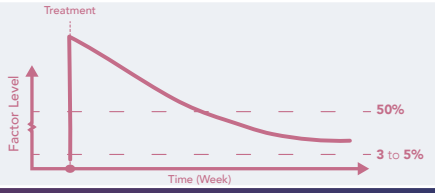
Approximate Representations of Factor Half-life



Factor levels increase immediately and decrease rapidly



Factor levels increase immediately and decrease rapidly



Factor levels increase immediately and decrease gradually between doses

Potential Safety Risks

Adverse Reactions

The most common adverse reactions are headache, diarrhea, cough, nausea, and joint pain.

Adverse reactions may vary between medications.

Hypersensitivity Reactions

Hypersensitivity reactions are unpredictable allergic reactions, including anaphylaxis. They may occur with any of the available clotting factor replacement therapies.

Thrombotic Events

Hem B only

Thrombotic events (eg. blood clots) have been reported following treatment with some clotting factor replacement therapies.

Inhibitors

Inhibitors are an immune response where the body develops antibodies that can bind to and stop the effects of replacement clotting factors.

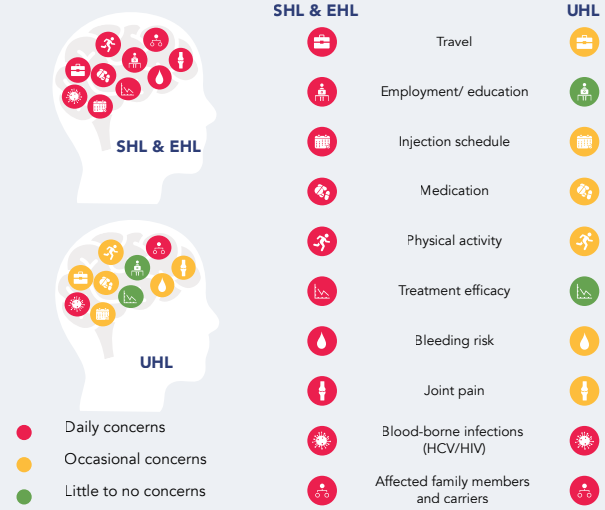
If inhibitors are going to occur they usually occur in the first 75 days of exposure to clotting factors. The rate of inhibitor development is unknown for UHL products.

Hem A
20 - 30%
of previously untreated patients

Hem B
3 - 5%
of previously untreated patients

Psychosocial Burden

Seeking a Hemophilia Free Mind

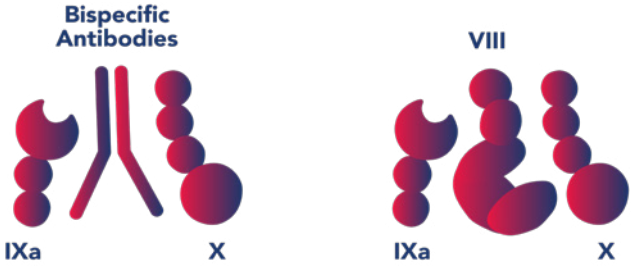


Modified from Krumb & Hermans; "Living with a "hemophilia-free mind" - the new ambition of hemophilia care?"; 2021

*Annual Bleed Rate is presented as the reported median for all bleeds, regardless of whether the bleed was spontaneous or traumatic or whether the bleed required treatment.
Data was sourced from the FDA, EMA, and Health Canada prescribing information and applicable and published Phase 3 clinical studies.
Values for SHL and EHL are presented as a range of values for the available products.
Last Update: March 2025.

Bispecific Antibody Therapy (hemophilia A only)

Bispecific antibody therapies belong to the non-factor replacement therapy class and are used to treat hemophilia A.[3] A bispecific antibody is a Y-shaped protein that can bring together two other proteins. In hemophilia, the bispecific antibody acts as a bridge between factor IXa and factor X, which helps the blood to clot more efficiently. This antibody bridge mimics the function of the missing activated factor VIII and, therefore, these therapies are often called factor VIIIa-mimetics.



Eligibility

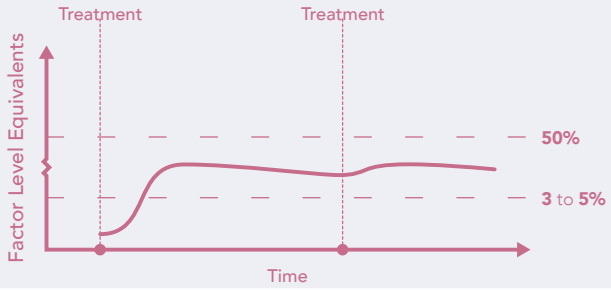
Approval Status	Year of First Approval	Approved Population
One product that is widely approved One product in phase 3	2017	All ages with and without inhibitors

Administration

Administration & Dosing	Location	Yearly Follow-up Schedule
1-4x/MONTH	Home or Treatment Center	1-2 Times per year and as needed

Efficacy

Median Annual Bleed Rate	% With Zero Bleeds	Factor Level (approximate representations of factor half-life)
<1.5 median for all bleeds, regardless of whether the bleed was treated, spontaneous, or traumatic	40-50% percentage with zero bleeds regardless of whether the bleed was treated, spontaneous, or traumatic	Factor levels will not change, but the effect is similar to having mild hemophilia

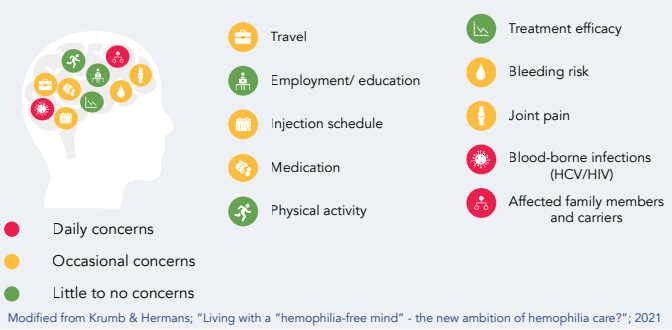


Safety Considerations / Potential Safety Risks

Adverse Reactions	Hypersensitivity Reactions	Inhibitors
The most common adverse reactions are injection site reactions, headache, and joint pain.	–	–
	Thrombotic Events	Elevated Liver Enzymes
	<1% *Occurred in patients receiving at least one dose of activated prothrombin complex concentrate (aPCC)	–

Psychosocial Burden

Seeking a Hemophilia Free Mind



Modified from Krumb & Hermans; "Living with a "hemophilia-free mind" - the new ambition of hemophilia care?"; 2021

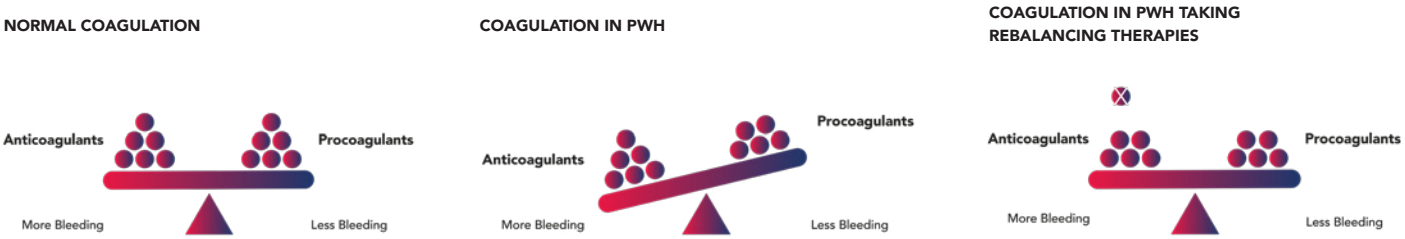
Data was sourced from the FDA, EMA, and Health Canada prescribing information and applicable and published Phase 3 clinical studies.
Last Update: March 2025.

aPCC, activated prothrombin complex concentrate.

Hemostatic Rebalancing Therapy

Rebalancing therapies aim to restore the disrupted balance between the levels of anticoagulation (i.e., anti-clotting) factors and clotting factors in the blood, thereby improving blood clotting.[3] These therapies can be used in people with hemophilia A or B, and people with or without inhibitors.

To understand how these medications work, we need to know more about how a blood clot forms. When someone is injured, their body's natural system stops the bleeding through activation of the clotting factors already present in the blood, and the generation of thrombin. People with hemophilia have no or low levels of clotting FVIII (hemophilia A), or FIX (hemophilia B) and low thrombin generation, so their blood cannot effectively clot. In other words, there is an imbalance between the factors that help the blood clot (clotting factors) and the factors that prevent clotting (anticoagulation factors). Rebalancing therapies help to restore this balance by decreasing the anticoagulation factor levels, which helps prevent bleeding events and restore normal blood clotting.[1] Each type of rebalancing therapy targets a different part of the coagulation system. If you are considering hemostatic rebalancing therapy, discuss with your healthcare team which is the best type for you.



Eligibility			Administration		
Approval Status	Year of First Approval	Approved Population	Administration & Dosing	Location	Yearly Follow-up Schedule
Two approved products One products in phase 3	2023	Adults (12+) with inhibitors *Indications vary by product	24 hr or 1x/WEEK 1x/MONTH	Home or Treatment Center	2 Every 6 months and as needed

Efficacy		
Median Annual Bleed Rate	% With Zero Bleeds	Factor Level (approximate representations of factor half-life)
<1.9 median for treated bleeds	Hem A: ~33% Hem B: ~42%	Treatment, Treatment, Factor Level Equivalent, 50%, 3 to 5%, Time Factor levels will not change, but the effect is similar to having mild hemophilia

Safety Considerations	Potential Safety Risks		Psychosocial Burden
Adverse Reactions	Hypersensitivity Reactions	Inhibitors	Seeking a Hemophilia Free Mind
The most common adverse reactions are related to the injection. Other common adverse reactions include headache.	<3%	–	Travel, Employment/ education, Injection schedule, Medication, Physical activity, Treatment efficacy, Bleeding risk, Joint pain, Blood-borne infections (HCV/HIV), Affected family members and carriers Daily concerns Occasional concerns Little to no concerns Modified from Krumb & Hermans; "Living with a "hemophilia-free mind" - the new ambition of hemophilia care?"; 2021
	Thrombotic Events Anti-TFPI agents may increase the risk of thrombotic events <1%* *Occurred in patients taking additional clotting agents		

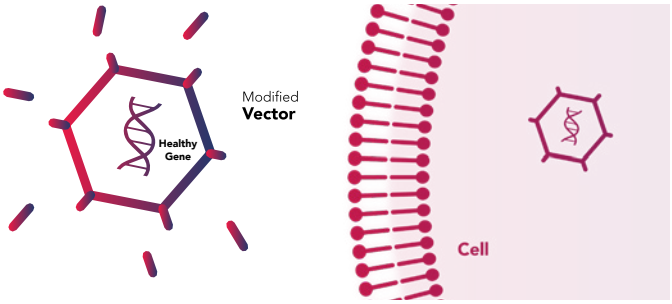
Data was sourced from the FDA, EMA, and Health Canada prescribing information and applicable and published Phase 3 clinical studies.
Last Update: March 2025.

Gene Therapy

Gene therapy is a new class of hemophilia treatment. Genes are the part of your genetic material (or DNA) that provide instructions for your cells to make specific proteins, like factor proteins. Gene therapy is a treatment that provides your cells with a working copy of a gene. For hemophilia, gene therapy provides your cells with a working copy of the FVIII gene (hemophilia A) or the FIX gene (hemophilia B), which allows your body to produce functioning clotting factors on its own and leads to long-term factor expression.

The corrected gene is delivered to the cells in something called a "vector." A vector is like a package that carries the functional gene to the cells that need it. This structure originally came from a virus but has been modified to remove the parts that could cause illness. Once the vector is inside the body, it targets the specific cells that need the working gene: in hemophilia, these are your liver cells. The functional gene is then processed by your cells to produce working clotting factor proteins. Gene therapy does not change your DNA but adds a healthy copy of the factor gene to your cells. Current therapies use adeno-associated viral (AAV) vectors, but there are multiple vector types, and there may be other delivery vectors in the future. After the vector has done its job and delivered the working gene, the added gene remains within the liver cells, and the vector leaves the body naturally through urine, feces, blood, saliva, and semen. This is called vector shedding.

Gene therapy can provide sustained and near-normal factor levels for years and eliminates the need for routine prophylaxis in the majority of people with hemophilia who receive treatment.[3]



Abnormal changes to liver enzymes

Most people with hemophilia A (80%), and some with hemophilia B (20%) will experience abnormal increases in liver enzyme levels following gene therapy.[3] These liver changes can be controlled with additional medications (e.g., corticosteroids or other immunosuppressive medications) for several weeks to months. There can be significant side effects associated with taking these medications, however they are generally manageable and reversible; your healthcare team is equipped to help you manage these side effects.

To promote liver health and prevent alcohol-related liver enzyme elevations, it is recommended that patients abstain from alcohol for at least one year, and thereafter limit their alcohol use.

WFH Gene Therapy Registry (GTR)

Through an international collaborative effort, the WFH has developed a global gene therapy patient registry. The aim of the GTR is to provide a robust, scientifically valid database, that is available to all healthcare providers treating people with hemophilia who receive gene therapy, anywhere in the world. The data collected through the WFH GTR will be used to assess the long-term safety and efficacy of gene therapy in people with hemophilia.

Contact gtr@wfh.org to learn more.

Each type of gene therapy has unique features that can affect how well it works in your body and whether it's the right choice for you. Your healthcare team can help you understand the different treatment options and how gene therapy might impact your life. Your healthcare team will consider your medical history, the severity of your hemophilia, and your personal preferences and goals to help you make an informed decision about gene therapy.

Eligibility

Approval Status	Year of First Approval	Approved Population
One approved product for hemophilia A One commercially available prodcut (two approved products) for hemophilia B	2022	Adults with hemophilia

Administration

Administration & Dosing	Location	Yearly Follow-up Schedule
Gene therapy is a one-time treatment	Specialized Treatment Center	Frequent follow-ups for 2-3 years after treatment

Hemophilia A

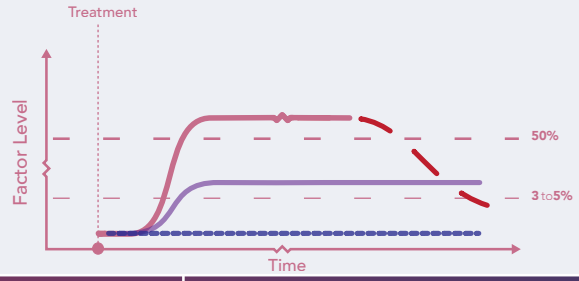
Efficacy

Median Annual Bleed Rate

<1

median for treated bleeds, regardless of whether the bleed was spontaneous or traumatic

Factor Level
(approximate representations of factor half-life)



In most cases, factor levels increase to a mild to normal range.

Some people do not respond,

have a low response,

or their factor levels decrease with time.

Safety Considerations

Adverse Reactions
The most common adverse reactions are infusion-related reactions, increased ALT, nausea, headache, above normal factor VIII(8) levels, tiredness, diarrhea, abdominal pain, and vomiting.

Potential Safety Risks

Hypersensitivity Reactions	Inhibitors	Thrombotic Events	Elevated Liver Enzymes
~ 5%	–	Potential for increased thromboembolic risk	~80% Long-term effects on liver health are unknown

Hemophilia B

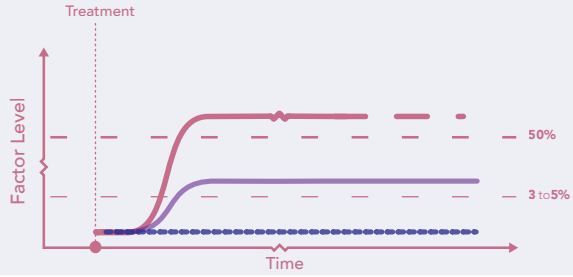
Efficacy

Median Annual Bleed Rate

<1

median for treated bleeds, regardless of whether the bleed was spontaneous or traumatic

Factor Level
(approximate representations of factor half-life)



In most cases, factor levels increase to a mild to normal range and are sustained long-term.

Some people do not respond,

or have a low response.

Safety Considerations

Adverse Reactions
The most common adverse reactions are increased ALT and AST, headache, blood creatine kinase elevations, flu-like symptoms, infusion-related reactions, fatigue, and malaise.

Potential Safety Risks

Hypersensitivity Reactions	Inhibitors	Thrombotic Events	Elevated Liver Enzymes
~ 4%	–	–	~20% Long-term effects on liver health are unknown

Psychosocial Burden: Seeking a Hemophilia Free Mind

- Travel
- Employment/ education
- Injection schedule
- Medication
- Physical activity
- Treatment efficacy
- Bleeding risk
- Joint pain
- Blood-borne infections (HCV/HIV)
- Affected family members and carriers

- Daily concerns
- Occasional concerns
- Little to no concerns

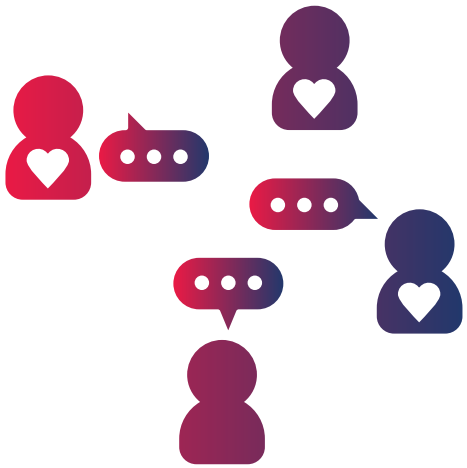
Modified from Krumb & Hermans; "Living with a "hemophilia-free mind" - the new ambition of hemophilia care?"; 2021

Data was sourced from the FDA, EMA, and Health Canada prescribing information and applicable and published Phase 3 clinical studies.
Last Update: March 2025.

ALT, alanine aminotransferase; AST, aspartate aminotransferase.

Step 4: Have conversations with others

You may decide to include others in your shared decision-making journey. These often include family, friends, peers, your patient organization, and caregivers. Pick a time that works for both parties and tell them about the shared decision-making process. You may want to share the information in this workbook, your thoughts about your current hemophilia treatment, your life goals and how they are impacted by your hemophilia, and how changing your therapy might impact your life.



Don't forget to bring your questions and this workbook to the meeting with your healthcare team.

Step 5: Prepare for visits with your healthcare provider

You may have come up with questions for your healthcare team as you progressed through the tool and read through the fact sheets. Write these questions down and bring them to your appointment to discuss them with your healthcare team.

Here is a list of questions you may want to ask

1. What treatment types are available to me?
2. Which specific products are available to me?
3. What is the process for switching to a new treatment?
4. Will this treatment be covered by my insurance?
5. Are there any expected future treatments I may be a better candidate for?
6. Will I still have to record my treatments?
7. What should I know about side effects and long-term or serious risks?
8. What will happen in the event of a bleed on this new treatment?
9. In your opinion, what are the benefits compared to my current treatment?
10. In your opinion, what are the drawbacks compared to my current treatment?

Step 6: Have an open and meaningful conversation with your healthcare team

Treatment choices	Pros Reasons why I might choose this treatment	Cons Reasons why I might not choose this treatment	What are the next steps?
Option 1: _____			
Option 2: _____			
Option 3: _____			

Step 7: Take time to consider your options

Switching treatments is an important decision that can affect you, your family, your lifestyle, and your overall health. Take the time you need to consider all treatment options available to you. We encourage you to revisit any of the steps and this workbook, or the online WFH SDM Tool and additional resources at any time in your decision-making journey.

Step 8: Meet with your healthcare team to make or confirm a decision about your treatment

Bring any remaining questions you have and discuss the next steps. You may decide to remain on your current treatment, modify your current treatment, change to a new treatment, or keep learning about your options. It is important to know that most treatment options allow you to return to the shared decision-making process at any time.

Making no treatment change is also a decision.

Notes

D Information

Resources on SDM

Ottawa Personal Decision Guides

These are designed to help people identify their decision-making needs, plan the next steps, track their progress, and share their views about health-related or social decisions.

Inventory of Shared Decision-Making Programs for Healthcare Professionals (Université Laval)

This inventory is a detailed list of international training activities from around the world that are designed for all kinds of healthcare professionals. The activities teach professionals about shared decision-making and help them integrate the approach into their daily practice.

Mayo Clinic Shared Decision-Making National Resource Center

The Shared Decision Making National Resource Center is involved in setting international standards for patient decision aids and promoting national and international dialogue about patient-centered care. They also work closely with the Minnesota Collaborative on Shared Decision Making.

National Institute for Health and Care Excellence: Shared decision making

This guide provides recommendations about how to put shared decision-making into practice.

Agency for Healthcare Research and Quality: The SHARE Approach

AHRQ's SHARE Approach is a five-step process for shared decision-making that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient.

National Learning Consortium: Shared Decision-Making Fact Sheet

This SDM fact sheet overviews the process of shared decision-making and has links to other resources.

Society for Medical Decision Making

The Society for Medical Decision Making is a not-for-profit, professional research organization and is the leading society for studying and advancing decision sciences in healthcare. SMDM publishes two peer-reviewed journals: Medical Decision-Making (MDM) and MDM Policy & Practice.

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3. Prescribing information and Phase 3 studies for approved gene therapy products. See the SDM Tool References Page.
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