

A. National Hemophilia Organization

Organization name	Czech Society of Hemophilia
City	Prague
Country	Czech Republic
Phone	+ 420 777 078 509
E-mail	info@hemofilici.cz
This form completed by:	First name Martin Last name Bohún Email m.bohun@hemofilici.cz

The WFH would like to know how you collect the data you are providing for this survey. If you have a registry, we would like to know more about the registry. A registry is a regularly updated centralized list of identified people with hemophilia (PWH) or inherited bleeding disorders. A registry includes information on demographics, diagnosis, treatment, and complications.

What is the source of the data provided for this survey?	Check all those that apply ☐ Hemophilia Society and/or NMO registry or database ☐ Hospital(s)/HTC(s) registry or database ☐ Health Ministry registry or database ☒ National registry ☐ National Insurance data ☐ Other (please describe):
How often is your database updated?	☒ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
Who updates the database?	☒ Doctors ☐ Patient organization ☐ Hospitals or clinics ☐ Clinician or clinical staff ☐ Other (please describe):
Have all the identified patients in your country been included in this report? If not, please explain.	Yes ☒ No ☐ Please explain:
Does your country have an established national registry for collecting data on patients with bleeding disorders?	Yes ☒ No ☐

B. Identified Patients

The sum of *Male*, *Female*, and *Sex Unknown* should be equal to Total.

For each bleeding disorder, the sum of all Male, Female, and Sex Unknown should be equal to the Total.

A woman who has $\leq 40\%$ of the normal level of clotting factor would be considered a person with hemophilia.

A woman with more than 40% FVIII is considered a carrier and should not be included in this question.

(Please DO NOT estimate or guess)	Total	Male	Female	Sex unknown	No data
1a. Total number of identified people with hemophilia A	941	914	27	0	☐
1b. Total number of identified people with hemophilia B	159	146	13	0	☐
1c. Total number of identified people with hemophilia type unknown	0	0	0	0	☐

2. Number of identified people with von Willebrand disease (VWD)	874	362	512	0	☐
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3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders).					
Factor I deficiency	0	0	0	0	☐
Factor II deficiency	3	1	2	0	☐
Factor V deficiency	20	6	14	0	☐
Factor V+VIII deficiency	1	0	1	0	☐
Factor VII deficiency	104	55	49	0	☐
Factor X deficiency	7	2	5	0	☐
Factor XI deficiency	38	16	22	0	☐
Factor XIII deficiency	1	0	1	0	☐
Rare factor deficiency: type unknown	27	7	20	0	☐
Platelet disorders: Glanzmann thrombasthenia					☒
Platelet disorders: Bernard Soulier Syndrome					☒
Platelet disorders: other or unknown					☒

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
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4a. Number of people with Hemophilia by age group

Age group	Number with hemophilia A	Number with hemophilia B	Number with hemophilia type unknown
0 - 4 years old	38	9	0
5 - 13 years old	138	26	0
14 - 18 years old	72	11	0
19 - 44 years old	352	52	0
45 - 64 years old	202	40	0
65 years or older	139	21	0
Age unknown	0	0	0
No age data	☐	☐	☐

The age distribution of Hemophilia A, B and unknown should be equal to the number of patients in 1. (If you do not know the age distribution, you can put that total number in the "Age unknown" box under the appropriate heading, hemophilia A, B or type unknown).

4b. Number of people with von Willebrand disease by age group

Age group	Number with VWD			
	Total	Male	Female	Sex Unknown
0 - 4 years old	19	8	11	0
5 - 13 years old	84	44	40	0
14 - 18 years old	53	26	27	0
19 - 44 years old	344	148	196	0
45 - 64 years old	250	86	164	0
65 years or older	124	50	74	0
Age unknown	0	0	0	0
No age data	☐	☐	☐	☐

The age distribution of vWD should be equal to the number of vWD in question 2. (If you do not know the age distribution, you can put that total number in the VWD age unknown box)

Do you consider these numbers to be accurate?	Yes ☒	Not sure ☐
5. Do you collect age data in a format that does not match question 4? (If you do collect age data in another format, please send it to the WFH in a separate attachment.)	Yes ☐	

6. Number of identified people with hemophilia by sex and severity

There are three levels of **severity** of hemophilia: **mild**, **moderate**, and **severe**. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

- A person (male or female) with >5-40 % of the normal amount of clotting factor has **mild** hemophilia.
- A person (male or female) with between 1-5 % of the normal amount of clotting factor has **moderate** hemophilia.
- A person (male or female) with less than 1 % of the normal amount of clotting factor has **severe** hemophilia.
- A woman who has ≤40% of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier.

6a. Severity of hemophilia in males

Type of hemophilia	Mild (factor level above 5%)	Moderate (factor level 1% to 5%)	Severe (factor level below 1%)	Severity unknown	No Data
Hemophilia A male	467	137	310	0	☐
18 and under	127	20	95	0	☐
Over age 18	340	117	215	0	☐
Hemophilia B male	39	52	55	0	☐
18 and under	15	9	17	0	☐
Over age 18	24	43	38	0	☐

6 b. Severity of hemophilia in females

Type of hemophilia	Carrier (factor level above 40%)	Mild (factor level 5% to 39%)	Moderate (factor level 1% to 5%)	Severe (factor level below 1%)	Severity unknown	No Data
Hemophilia A female	50	24	0	3	0	☐
18 and under	2	6	0	0	0	☐
Over age 18	48	18	0	3	0	☐
Hemophilia B female	9	12	1	0	0	☐
18 and under	0	5	0	0	0	☐
Over age 18	9	7	1	0	0	☐

The sum of Hemophilia A Male mild, moderate, severe and unknown should be equal to number of Hemophilia A Male in question 1.
 The sum of Hemophilia A Female mild, moderate, severe and unknown should be equal to number of Hemophilia A female in question 1.

The sum of Hemophilia B Male mild, moderate, severe and unknown should be equal to number of Hemophilia B Male in question 1.
 The sum of Hemophilia B Female mild, moderate, severe and unknown should be equal to number of Hemophilia B female in question 1.

Do you consider these numbers to be accurate?	Yes ☒	Not sure ☐
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7. Number of severe VWD patients

	Total number of severe (type 3) VWD patients	No data	Number of type 3 VWD patients receiving prophylaxis with factor concentrate	No data
Total	22	☐	12	☐
Male	9	☐	5	☐
Female	13	☐	7	☐
Unknown	0	☐	0	☐

Do you consider these numbers to be accurate?	Yes ☒	Not sure ☐
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8. INHIBITORS: Number of identified people with current clinically significant inhibitors in 2025. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	No data	New cases of inhibitors in 2025	No data
Hemophilia A	14	☐	1	☐
Hemophilia B	3	☐	1	☐
von Willebrand Disease (congenital)	0	☐	0	☐

9 A. Availability and usage of products to treat hemophilia

Treatment product	Product is available	Number of patients treated with product indicated	No data
Plasma	☒	0	☐
Cryoprecipitate	☒	0	☐
Plasma-derived concentrate	☒	26	☐
Recombinant concentrate (excluding extended half-life)	☒	48	☐
Recombinant concentrate, extended half-life	☒	418	☐
DDAVP (Desmopressin)	☒	0	☐
Altuviiio/Altuvoc	☒	114	☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

9 B. Availability and usage of non-factor products to treat hemophilia with inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Emicizumab (Hemlibra)	☒	14	☐
Re-balancing Agents (Fitusiran, Concizumab, Marstacimab)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

9 C. Availability and usage of non-factor products to treat hemophilia without inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Emicizumab (Hemlibra)	☒	115	☐
Re-balancing Agents (Fitusiran, Concizumab, Marstacimab)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

10. Availability and usage of products to treat VWD

Treatment product	Product is available	Number of patients treated with product indicated				No data
		Total	Male	Female	Unknown	
Plasma	☒	0	0	0	0	☐
Cryoprecipitate	☒	0	0	0	0	☐
Plasma-derived concentrate	☒	136	49	87	0	☐
DDAVP (Desmopressin)	☒	1	0	1	0	☐
Nasal	☐					☐
IV/Subcutaneous	☒	1	0	1	0	☐
Recombinant concentrate	☐					☐
Tranexamic acid	☐					☐
Hormonal therapy	☐					☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

11. HIV infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders	No data
Total number of people living with HIV	1	0	0	☐
New HIV infections in 2025	0	0	0	☐

12. Hepatitis C infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders	No data
Total number of people infected with hepatitis C ¹	160	7	0	☐
Total number of people with currently active hepatitis C ²	26	1	0	☐
New hepatitis C infections in 2025	0	0	0	☐

¹Hepatitis C antibody positive at any time

²Still PCR positive: patients who have not cleared the virus spontaneously or after treatment

13. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2025)

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other inherited bleeding disorders	No data
Bleeding	0			☐
HIV	0			☐
Liver disease	1			☐
Other causes	3			☐

C. Hemophilia Care System in Your Country

We define Hemophilia Treatment Centre (HTC) as a medical centre providing clinical care and serving the needs for people with hemophilia and related disorders (including diagnosis and treatment).

Hemophilia Comprehensive Care Centres are defined as a hemophilia treatment centre providing comprehensive care involving multidisciplinary medical services necessary for the diagnosis, treatment and management of the condition and its complications. Comprehensive care includes access to hospital-based nursing staff, physical therapy services, social workers, dental services, obstetric and gynecological services, psychosocial services, home therapy, inhibitor care and immune tolerance services, genetics laboratory, genetic counselling, HIV, and hepatitis care. They can also include 24/7 availability of expert care (i.e., a doctor with hemophilia expertise is on call at all times).

14. How many hemophilia treatment centres are there in total in your country?	10
How many of the hemophilia treatment centres you have indicated above are Hemophilia Comprehensive Care Centres?	3
What percentage of the hemophilia patients in your country has access to a hemophilia treatment centre:	100

Prophylaxis is regular, long-term treatment with a hemostatic agent to prevent bleeds. Please indicate the number and percentage of patients who are on prophylaxis and state whether the values provided are precise or an estimate.

	Number	Percentage		
15. Children (18 and under) with severe hemophilia on prophylaxis	109	97	Precise: ☒ Estimate: ☐	Not known ☐
Adults (over age 18), with severe hemophilia on prophylaxis	226	84	Precise: ☒ Estimate: ☐	Not known ☐
Patients of all ages with von Willebrand disease (VWD) type 3 on prophylaxis	10		Precise: ☒ Estimate: ☐	Not known ☐

Immune tolerance induction (ITI) is the administration of FVIII or FIX concentrate in patients with inhibitors to eradicate the inhibitors.

16. What is the total number of patients with inhibitors who received ITI during the last year?	0	Precise: ☒ Estimate: ☐	Not known ☐
Of this total, how many were new patients who started ITI treatment during the last year?	0	Precise: ☒ Estimate: ☐	Not known ☐

Recombinant factor VIIa and FEIBA are administered to treat and prevent bleeding in people with hemophilia (with Factor VIII or IX deficiency) who have developed antibodies against replacement coagulation factor.

17 a) What is the total number of patients with inhibitors who received factor VIIa during the last year?	3	Precise: ☒ Estimate: ☐	Not known ☐
17 b) What is the total number of patients with inhibitors who received FEIBA during the last year?	0	Precise: ☒ Estimate: ☐	Not known ☐

D. The Cost and Use of Treatment

Please enter only numbers and do not use punctuation or special characters.

18 A. Annual usage of purchased factor concentrates (please do not include donated factor)	Factor VIII	Not known	Factor IX	Not known
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2025 (excluding donated factor)?	57 517 245	☐	7 812 172	☐
Plasma derived: How many international units of plasma-derived concentrates were used in your country in 2025 (excluding donated factor)?	2 031 495	☐	297 561	☐
Recombinant, excluding extended half-life: How many international units of recombinant concentrates (excluding extended half-life) were used in your country in 2025 (excluding donated factor)?	3 885 196	☐	0	☐
Recombinant, extended half-life: How many international units of recombinant concentrates, extended half-life were used in your country in 2025 (excluding donated factor)?	51 600 554	☐	7 514 611	☐
If factor concentrates are purchased in your country but you are unable to report the quantities please check here:	☐		☐	

The Total of FVIII should be equal to sum of FVIII plasma-derived and FVIII recombinant

The Total of FIX should be equal to sum of FIX plasma-derived and FIX recombinant

18 B. Annual usage of donated factor concentrates	Factor VIII	Not known	Factor IX	Not known
How many international units of donated factor concentrates (plasma-derived or recombinant) from all sources, including Humanitarian Aid , were used in your country in 2025?	0	☐	0	☐

	Amount	Not known
18 C. How many milligrams (mg) of Hemlibra were purchased in your country in 2025? (Excluding donated product)	522 432	☐
18 D. How many international units (IU) of Altuviiio/Altuvoc were purchased in your country in 2025? (excluding donated product)	8 017 586	☐
18 E. How many milligrams (mg) of Re-balancing Agents (Fitusiran, Concizumab, Marstacimab) were purchased in your country in 2025? (excluding donated product)		☐
18 F. How many milligrams (mg) of FVIIa were purchased in your country in 2025? (excluding donated product)	2 045	☐
18 G. How many international units (IU) of FEIBA were purchased in your country in 2025? (excluding donated product)	0	☐

19. Gene Therapy	In 2025	Not known	Anytime	Not known
How many people in your country have received gene therapy?	0	☐	0	☐

Do you consider these numbers to be accurate?	Yes ☒	Not sure ☐
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PLEASE NOTE: If a product used in your country is not listed, please add it at the bottom of the appropriate table.

Currency:	Tax included? No ☐ Yes ☐	Tax rate:	Not data ☐
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20. Factor VIII Concentrates used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in the currency used to purchase the product. Please indicate if this price includes tax.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aafact	Sanquin	
☐	Advate rAHF PFM	Takeda	
☐	Adynovate = Adynovi	Takeda	
☐	Afstyla	CSL Behring	
☐	Alphanate	Grifols	
☐	ALTUVIIIIO	Sanofi, SOBI	
☐	Amofil	Sanquin OY	
☐	Beriate P	CSL Behring	
☐	Conco-eight-HT	Benesis	
☐	Confact F	Kaketsuken	
☐	Cross Eight M	Japanese Red Cross	
☐	Elocta (= Eloctate)	Sanofi, SOBI	
☐	Emoclot D.I.	Kedrion	
☐	FACTANE	LFB	
☐	Factor 8 Y	BioProducts Lab.	
☐	Faktor VIII SDH Intersero	Intersero	
☐	Fanhdi	Grifols	
☐	GreenEight	Green Cross	
☐	GreenGene	Green Cross	
☐	GreenMono	Green Cross	
☐	Haemoctin SDH	Biotest	
☐	Haemosolvate Factor VIII	National Bioproducts	
☐	HEMO-8R	HEMOBRAS	
☐	Hemofil M AHF	Takeda	
☐	HEMORAAS SD plus H	Shanghai RAAS	
☐	HEMORAAS-HP, SD plus H	Shanghai RAAS	
☐	HEMORAAS-IP, SD plus H	Shanghai RAAS	
☐	Humafaktor 8	Human BioPlazma	
☐	Human Coagulation Factor VIII	Baltijas Terapeitiskais Serviss	
☐	Jivi	Bayer	
☐	Koate DVI	Kedrion (Talecris)	
☐	Kovaltry	Bayer	
☐	Novoeight (= Zonavate)	Novo Nordisk	
☐	Nuwiq	Octapharma	
☐	Obizur	Takeda	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Octavi SD	Octapharma	
☐	Octofactor	Generium/Pharmstandart	
☐	Optivate	Bio Products Laboratory	
☐	Pharmavate	Pharma Innovations	
☐	Recombinate rAHF	Takeda	
☐	ReFacto AF (=Xyntha)	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	SaFacto AF	Saman Daroo 8	
☐	TBSF High Purity Factor VIII/Von Willebrand Factor	CSL Behring	

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☐	Factor VIII Antihemofílico UNC	Laboratorio de Hemoderivados Farmaceutico UNC	
☐	Vihuma	Biotest	
☐	Veyvondi	Takeda	
☐	Wilate	CSL Behring	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

21. Factor IX Concentrates used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aimafix	Kedrion	
☐	AlphaNine SD	Grifols	
☐	Alprolix	Sanofi	
☐	BeneFIX	Pfizer (Wyeth)	
☐	Berinin-P = Berinin HS	CSL Behring	
☐	BETAFACT	LFB	
☐	Christmassin-M	Benesis	
☐	Clotnine	Hemarus	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Fixnove	Takeda	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Humafactor IX	Kedrion	
☐	Idelvion	CSL Behring	
☐	Immunine	Takeda	
☐	Ixinity	Medexus Pharma (Aptevo BioTherapeutics)	
☐	MonoFIX-VE	CSL Behring	
☐	Mononine	CSL Behring	
☐	Nanofix	Octapharma	
☐	Nanotiv	Octapharma	
☐	Nonafact	Sanquin	
☐	Novact M	Kaketsuken	
☐	Octafix	Octapharma	
☐	Octanine F	Octapharma	
☐	Rebinyon (= Refixia)	Novo Nordisk	
☐	Replenine – VF	BioProducts Lab.	
☐	Rixubis	Takeda	
☐	TBSF High Purity Factor IX Concentrate	CSL Behring	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

22. Prothrombin Complex Concentrates used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Beriplex P/N (= Confidex, Kcentra)	CSL Behring	
☐	Cofact	Sanquin	
☐	Complejo Protrombínico UNC	Laboratorio de Hemoderivados Farmaceutico UNC	
☐	Facnyne	Green Cross	
☐	Haemosolvex Factor IX	National Bioproducts	

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☐	HT DEFIX	SNBTS	
☐	Kanokad	LFB	
☐	KASKADIL	LFB	
☐	Octaplex	Octapharma	
☐	PPSB-HT	Nihon Pharmaceutical	
☐	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
☐	Profilnine SD	Grifols	
☐	Proplex T	Takeda	
☐	Protexel	LFB	
☐	Prothrombinex PXT	CSL Behring	
☐	Prothrombinex-HT	CSL Behring	
☐	Prothrombinex-VF	CSL Behring	
☐	Prothromplex-T	Takeda	
☐	Prothroras	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

23. Antithrombin products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aclotine	LFB	
☐	ATIII	Bio Products Laboratory	
☐	Antitrombina III UNC Pasteurizada	Laboratorio de Hemoderivados Farmaceutico UNC	
☐	Atryn	GTC Biotherapeutics	
☐	Anbinex	Grifols	
☐	Kybernin P	CSL Behring	
☐	Neuart	Benesis	
☐	Thrombate III	Grifols	
☐	Thrombotrol-VF	CSL Behring	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

24. Factor VII products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aryoseven	Aryogen	
☐	Byclot	Kaketsuken	
☐	Cevenfacta (= Sevenfact)	LFB	
☐	Coagil 7	Pharmstandard	
☐	FACTEUR VII	LFB	
☐	Factor VII	Takeda	
☐	Factor VII	Bio Products Laboratory	
☐	NovoSeven (= Niasase RT)	Novo Nordisk	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

25. Von Willebrand Factor products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aleviate (Biostate)	CSL Behring	
☐	Bioclot A	Biofarma	
☐	Eqwilate	Octapharma	

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☐	Haemate P (=Humate P, Haemate HS)	CSL Behring	
☐	Veyvondi (=Vonvendi)	Takeda	
☐	Voncento	CSL Behring	
☐	WILFACTIN, Willfact	LFB	
☐	Wilstart	LFB	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

26. Desmopressin products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	DDAVP (nasal spray)	Ferring	
☐	DDAVP (IV injection)	Ferring	
☐	DDAVP (SC injection)	Ferring	
☐	Minrin (nasal spray)	Ferring	
☐	Minrin (IV injection)	Ferring	
☐	Minrin (SC injection)	Ferring	
☐	Octim (nasal spray)	Ferring	
☐	Octim (IV injection)	Ferring	
☐	Octim (SC injection)	Ferring	
☐	Octostim (nasal spray)	Ferring	
☐	Octostim (IV injection)	Ferring	
☐	Octostim (SC injection)	Ferring	
☐	Stimate (nasal spray)	Ferring	
☐	Other nasal spray:		
☐	Other IV injection:		
☐	Other SC injection:		
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

27. Fibrinogen products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Clottafact	LFB	
☐	Clottagen	LFB	
☐	Fibclot	LFB	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS)	CSL Behring	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Fibryga	Octapharma	
☐	Haemocomplettan P= Haemocomplettan HS	CSL Behring	
☐	Riastap	CSL Behring	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

28. Non-factor products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Hemlibra (emicizumab)	Chugai, Roche, Genentech	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

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29. Rebalancing agents used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Alhemo (concizumab)	Novo Nordisk	
☐	Fitusiran	Sanofi	
☐	Concizumab	Novo Nordisk	
☐	Marstacimab	Pfizer	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

30. Gene therapy products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Roctavian	BioMarin Pharmaceutical	
☐	Hemgenix	CSL Behring and Unique	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

31. Other Products used in 2025

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Anact C (activated protein C)	Kaketsuken	
☐	Ceproin	Takeda	
☐	Cluvot (= Cluviat, Corifact, Fibrogammin HS, Fibrogammin P)	CSL Behring	
☐	Coagadex	Bio Products Laboratory	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products Laboratory	
☐	FEIBA	Takeda	
☐	Fibclot	LFB	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	HEMOLEVEN (FXI)	LFB	
☐	Octaplas	Octapharma	
☐	Riastap	CSL Behring	
☐	Tretten (= NovoThirteen)	Novo Nordisk	
☐	Veyvondi (= Vonvendi)	Takeda	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

Please return to:

 Email: globalsurvey@wfh.org

 Address: **World Federation of Hemophilia**

1184 rue Sainte-Catherine Ouest, Bureau 500

Montréal, Québec, H3B 1K1

Canada

Please provide your feedback on the WFH Annual Global Survey data collection system.

Comments:

Glossary of terms

Bernard-Soulier syndrome: A severe congenital bleeding disorder characterized by thrombocytopenia and large platelets, due to a defect in the platelet glycoprotein 1b/V/IX receptor.

Cryoprecipitate: A fraction of human blood prepared from fresh plasma. Cryoprecipitate is rich in factor VIII, von Willebrand factor, and fibrinogen (factor I). It does not contain factor IX.

Desmopressin (DDAVP): A synthetic hormone used to treat most mild cases of von Willebrand disease and mild hemophilia A. It is administered intravenously or by subcutaneous injection or by intranasal spray.

Extended half-life factor concentrate: A new generation of recombinant factor concentrates, which extend their half-life. Half-life is the time it takes for infused factor to lose half of its potency. Traditional factor VIII has a half-life of 8 to 12 hours; an extended factor VIII half-life is defined as a ratio greater than 1.3-fold, of the traditional half-life.

Factor concentrates: These are fractionated, freeze-dried preparations of individual clotting factors or groups of factors derived from donated blood.

Glanzmann's thrombasthenia: A severe congenital bleeding disorder in which the platelets lack glycoprotein IIb/IIIa, the blood platelet count is normal, but their function is very abnormal.

Hemophilia A: A condition resulting from factor VIII deficiency, also known as classical hemophilia.

Hemophilia B: A condition resulting from factor IX deficiency, also known as Christmas disease.

Hemophilia treatment centre: A specialized medical centre that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders.

HIV: Human immunodeficiency virus. The virus that causes AIDS.

Identified person: A living person known to have hemophilia, von Willebrand disease, or another bleeding disorder.

Inhibitors: A PWH has inhibitors when their body's immune system attacks the molecules in factor concentrate, rendering it ineffective.

International Unit (IU): A standardized measurement of the amount of factor VIII or IX contained in a vial. Usually marked on vials as 250 IU, 500 IU, 1000 IU or 2000 IU.

Mild hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity below normal but above 5% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%. The normal range of factor VIII or IX is 50 to 200%)

Moderate hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity between 1 to 5 % of normal activity in the bloodstream.

Plasma-derived products: Factor concentrates that contain factor VIII or IX that have been fractionated from human blood.

PWH: Person with hemophilia

Recombinant products: Factor concentrates that contain factor VIII or IX that have been artificially produced and are, therefore, not derived from human blood.

Registry: A database or record of identified people with hemophilia or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment and complications.

Severe hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity of less than 1 % in the bloodstream.

von Willebrand disease (VWD): An inherited bleeding disorder resulting from a defect or deficiency of von Willebrand factor.