

**WFH**

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

Annual Global Survey 2015

Please return to WFH by May 30, 2016

A. National Hemophilia Organization

Organization name	Czech Society of Hemophilia
City	Prague
Country	Czechia
Phone	+420603580980
E-mail	info@hemofilici.cz
This form completed by:	First name Vladimír Last name Dolejš Email vladimir@dolejs.org

Please [Click Here](#) to validate Organization contact information

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 personal details, diagnosis, treatment, and complications.

What is the source of the numbers provided for this survey?	Check one <input type="checkbox"/> Hemophilia Society and/or NMO registry or database <input checked="" type="checkbox"/> Hospital(s)/HTC(s) registry or database <input type="checkbox"/> Health Ministry registry or database <input type="checkbox"/> Other (please describe):
How often is your database updated?	<input checked="" type="checkbox"/> Ongoing update (can be updated anytime) <input type="checkbox"/> Yearly update (the registry is updated once each year) <input type="checkbox"/> Other (please describe):
Who updates the database?	<input checked="" type="checkbox"/> Doctors update the database <input type="checkbox"/> Patient organization updates the database <input type="checkbox"/> Hospitals or clinics update the database <input type="checkbox"/> Other (please describe):
What percentage of the patient population in your country are you reporting on? Please provide your best estimate	<input checked="" type="checkbox"/> 100 Percentage <input type="checkbox"/> Not Known

Please [Click Here](#) to validate Data source

B. Identified Patients

(Please DO NOT estimate or guess)	Number	Not known
1. Total number of identified people with hemophilia A or B , or type unknown (PWH)	1067	<input type="checkbox"/>
2. Number of identified people with von Willebrand disease (VWD)	810	<input type="checkbox"/>
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders. See question 6 for the list of specific disorders.)	91	<input type="checkbox"/>
Do you consider these numbers to be accurate?	Yes <input checked="" type="checkbox"/>	Not sure <input type="checkbox"/>

Please [Click Here](#) to validate number of patients



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

Age group	Number with hemophilia A	Number with hemophilia B	Number with hemophilia type unknown	Number with VWD
0 - 4 years old	45	9	0	9
5 - 13 years old	101	20	0	64
14 - 18 years old	63	8	0	43
19 - 44 years old	432	48	0	377
45 years or older	290	51	0	317
Patients with age Unknown	0	0	0	0
No age data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The age distribution of Hemophilia A, B and unknown should be equal to the number of PWH in question B1

The age distribution of vWD should be equal to the number of vWD in question B2

Do you consider these numbers to be accurate?	Yes <input type="checkbox"/>	Not sure <input checked="" type="checkbox"/>
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 <input type="checkbox"/>

Please [Click Here](#) to validate Age section

6. Type of hereditary bleeding disorder

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

Diagnosis	Total	Male	Female	Gender unknown	No data
Hemophilia A	931	931	0	0	<input type="checkbox"/>
Hemophilia B	136	136	0	0	<input type="checkbox"/>
Hemophilia, type unknown	0	0	0	0	<input type="checkbox"/>
von Willebrand disease	810	236	281	293	<input type="checkbox"/>
Factor I deficiency	0	0	0	0	<input checked="" type="checkbox"/>
Factor II deficiency	1	0	1	0	<input type="checkbox"/>
Factor V deficiency	5	1	4	0	<input type="checkbox"/>
Factor V+VIII deficiency	0	0	0	0	<input type="checkbox"/>
Factor VII deficiency	39	17	22	0	<input type="checkbox"/>
Factor X deficiency	4	3	1	0	<input type="checkbox"/>
Factor XI deficiency	21	11	10	0	<input type="checkbox"/>
Factor XIII deficiency	2	1	1	0	<input type="checkbox"/>
Rare factor deficiency: type unknown	22	7	15	0	<input type="checkbox"/>
Platelet disorders: Glanzmann's thrombasthenia					<input checked="" type="checkbox"/>
Platelet disorders: Bernard Soulier Syndrome					<input checked="" type="checkbox"/>
Platelet disorders: other or unknown					<input checked="" type="checkbox"/>

The sum of Totals Hemophilia A, B, and type unknown should be equal to the number of PWH in question B1.

The Total of vWD should be equal to the number of vWD in question B2.

The sum of Total of the all other bleeding and platelets disorders should be equal to the number of OBD in question B3

A woman who has less than 40 percent 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 report.

Do you consider these numbers to be accurate?	Yes <input checked="" type="checkbox"/>	Not sure <input type="checkbox"/>
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Please [Click Here](#) to validate Gender section



7. How are patients with rare bleeding disorders (deficiency in FI, FII, FV, FV+VIII, FVII, FX, FXI FXIII) classified?

Factor level measurements <input checked="" type="checkbox"/>	Clinical diagnosis <input type="checkbox"/> (bleeding, family history)	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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How are patients with von Willebrand Disease classified?

Factor level measurements <input checked="" type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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8. Number of identified people with hemophilia by gender 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 per cent of the normal amount of clotting factor has **mild** hemophilia.
- A person (male or female) with between 1-5 per cent of the normal amount of clotting factor has **moderate** hemophilia.
- A person (male or female) with less than 1 per cent of the normal amount of clotting factor has **severe** hemophilia.
- A woman who has less than 40 percent 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 report.

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	439	149	307	36	<input type="checkbox"/>
Hemophilia A female	0	0	0	0	<input checked="" type="checkbox"/>
Hemophilia B male	33	46	49	8	<input type="checkbox"/>
Hemophilia B female	0	0	0	0	<input checked="" type="checkbox"/>

The sum of Hemophilia A Male mild, moderate, severe and unknown should be equal to number of Hemophilia A Male in question 6

The sum of Hemophilia A Female mild, moderate, severe and unknown should be equal to number of Hemophilia A female in question 6

The sum of Hemophilia B Male mild, moderate, severe and unknown should be equal to number of Hemophilia B Male in question 6

The sum of Hemophilia B Female mild, moderate, severe and unknown should be equal to number of Hemophilia B female in question 6

Do you consider these numbers to be accurate?	Yes <input checked="" type="checkbox"/>	Not sure <input type="checkbox"/>
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9. Number of severe VWD patients

Total number of severe (type 3) VWD patients	Number of VWD patients receiving replacement therapy	Number of VWD patients with severe bleeding symptoms	No Data
20	139	50	<input type="checkbox"/>

Do you consider these numbers to be accurate?	Yes <input type="checkbox"/>	Not sure <input checked="" type="checkbox"/>
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10. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2015	No Data
Hemophilia A	19	3	<input type="checkbox"/>
Hemophilia B	2	0	<input type="checkbox"/>

Please [Click Here](#) to validate classification, severity and inhibitors



11. Availability and usage of products to treat hemophilia

Treatment product	Product is available	Product is used	Number of patients treated with product indicated	No data
Plasma	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Cryoprecipitate	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Plasma-derived concentrate	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	407	<input type="checkbox"/>
Recombinant concentrate (excluding prolonged half-life)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	201	<input type="checkbox"/>
Recombinant concentrate (prolonged half-life)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
DDAVP (Desmopressin)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

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

12. Availability and usage of products to treat VWD

Treatment product	Product is available	Product is used	Number of patients treated with product indicated	No data
Plasma	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Cryoprecipitate	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
Plasma-derived concentrate	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	139	<input type="checkbox"/>
DDAVP (Desmopressin)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

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

13. HIV infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people living with HIV	3	0	0
New HIV infections in 2015	0	0	0

14. Hepatitis C infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people infected with hepatitis C ¹	210	2	0
Total number of people with currently active hepatitis C ²	62	1	0
New hepatitis C infections in 2015	0	0	0

¹Hepatitis C antibody positive at any time

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



15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2015)

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
Bleeding	3	0	0
HIV	0	0	0
Liver disease	0	0	0
Other causes	3	1	0

Please [Click Here](#) to validate products, HIV, HCV, and cause of death sections

C. Hemophilia Care System in Your Country

We define as Hemophilia Treatment Centre (HTC) a medical centre providing any level of care (including basic diagnosis and treatment) for inherited bleeding disorders. Please provide the number of all such centres in your country. Please also indicate how many of those centers have **direct access, within the same structure**, to at least the following: hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory.

16. How many hemophilia treatment centres are there in total in your country?	9
How many of the hemophilia treatment centres you have indicated above have direct access, within the same structure , to a hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory?	9
Which percentage of the hemophilia patients in your country has access to a hemophilia treatment centre:	100

Prophylaxis is regular, long-term treatment with clotting factor concentrates to prevent bleeds. Please indicate if the percentage provided is precise or an estimate.

17. What percentage of children (under age 18) with severe hemophilia are on prophylaxis?	92	Precise: <input checked="" type="checkbox"/> Estimate: <input type="checkbox"/>	Not known <input type="checkbox"/>
What percentage of adults (over age 18), with severe hemophilia are on prophylaxis?	55	Precise: <input checked="" type="checkbox"/> Estimate: <input type="checkbox"/>	Not known <input type="checkbox"/>
What is the most common dose (IU/kg) of factor administered and frequency?	18 IU/kg 3 times per week		

Immune tolerance induction (ITI) is the administration of FVIII or FIX concentrate in patients with inhibitors to eradicate the inhibitors. Please indicate the total percentage of patients with inhibitors receiving ITI in your country and the number of patients having received ITI during last year and indicate if what you provided is precise or an estimate.

18. What percentage of patients with inhibitors are receiving or have ever received immune tolerance induction?	30	Precise: <input type="checkbox"/> Estimate: <input checked="" type="checkbox"/>	Not known <input type="checkbox"/>
How many patients with inhibitors have received immune tolerance induction in the last year?	4	Precise: <input checked="" type="checkbox"/> Estimate: <input type="checkbox"/>	Not known <input type="checkbox"/>

Please [Click Here](#) to validate Care section

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D. The Cost and Use of Factor Concentrates

19 A. Annual usage of purchased factor concentrates (please do not include humanitarian aid)	Factor VIII	Not known	Factor IX	Not known
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2015 (excluding humanitarian aid)?	51 064 250	<input type="checkbox"/>	6 816 005	<input type="checkbox"/>
How many international units of plasma-derived concentrates were used in your country in 2015 (excluding humanitarian aid)?	27 295 500	<input type="checkbox"/>	6 460 496	<input type="checkbox"/>
How many international units of recombinant concentrates were used in your country in 2015 (excluding humanitarian aid)?	23 768 750	<input type="checkbox"/>	355 509	<input type="checkbox"/>

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

19 B. Annual usage of donated factor concentrates	Factor VIII	Not known	Factor IX	Not known
How many international units of humanitarian aid (plasma-derived or recombinant) concentrates were used in your country in 2015?	0	<input type="checkbox"/>	0	<input type="checkbox"/>

Do you consider these numbers to be accurate?	Yes <input checked="" type="checkbox"/>	Not sure <input type="checkbox"/>
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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: CZK	Tax included? No <input type="checkbox"/> Yes <input type="checkbox"/>	Tax rate:
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Please [Click Here](#) to validate Factors section



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20. Factor VIII Concentrates used in 2015

(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
<input type="checkbox"/>	Aafact	Sanquin	
<input type="checkbox"/>	Advate rAHF PFM	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Adynovate	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Aleviate	CSL Behring	
<input type="checkbox"/>	Alphanate	Grifols	
<input type="checkbox"/>	Amofil	Sanquin OY	
<input type="checkbox"/>	Beriate P	CSL Behring	
<input type="checkbox"/>	BIOSTATE	CSL Bioplasma	
<input type="checkbox"/>	Conco-eight-HT	Benesis	
<input type="checkbox"/>	Confact F	Kaketsuken	
<input type="checkbox"/>	Cross Eight M	Japanese Red Cross	
<input type="checkbox"/>	Elocta/Eloctate	Biogen Idec	
<input type="checkbox"/>	Emoclot D.I.	Kedrion	
<input type="checkbox"/>	FACTANE	LFB	
<input type="checkbox"/>	Factor 8 Y	BioProducts Lab.	
<input type="checkbox"/>	Faktor VIII SDH Intersero	Intersero	
<input type="checkbox"/>	Fanhdi	Grifols	
<input type="checkbox"/>	GreenEight	GreenCross	
<input type="checkbox"/>	GreenGene	GreenCross	
<input type="checkbox"/>	GreenMono	Greencross Corp	
<input type="checkbox"/>	Haemate P (= Haemate HS)	CSL Behring	
<input type="checkbox"/>	Haemoctin SDH	Biotest	
<input type="checkbox"/>	Haemosolvate Factor VIII	National Bioproducts	
<input type="checkbox"/>	Helixate NexGen = Helixate FS	CSL Behring	
<input type="checkbox"/>	Hemofil M AHF	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	HEMORAAS SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-HP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-IP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	Humate P	CSL Behring	
<input type="checkbox"/>	Humafaktor 8	Human BioPlazma	
<input type="checkbox"/>	Human Coagulation Factor VIII	Baltijas Terapeitiskais Serviss	
<input type="checkbox"/>	Immunate	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Koate DVI	Talecris	
<input type="checkbox"/>	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	

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<input type="checkbox"/>	Monoclote P	CSL Behring	
<input type="checkbox"/>	Novoeight	NovoNordisk	
<input type="checkbox"/>	Nuwiq	Octapharma	
<input type="checkbox"/>	Octanate	Octapharma	
<input type="checkbox"/>	Octanativ-M	Octapharma	
<input type="checkbox"/>	Octavi SD	Octapharma	
<input type="checkbox"/>	Optivate	Bio Products Laboratory	
<input type="checkbox"/>	FVIII by Quimbiotec	Quimbiotec	
<input type="checkbox"/>	Recombinate rAHF	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	ReFacto AF	Pfizer (Wyeth)	
<input type="checkbox"/>	Replenate	Bio Products Laboratory	
<input type="checkbox"/>	UNC Hemoderivados	Laboratorio de Hemoderivados de Universidad Nacional de Córdoba	
<input type="checkbox"/>	Voncento	CSL Behring	
<input type="checkbox"/>	Wilate	Octapharma	
<input type="checkbox"/>	Xyntha	Pfizer (Wyeth)	
<input type="checkbox"/>	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.**21. Factor IX Concentrates used in 2015**

(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
<input type="checkbox"/>	Aimafix	Kedrion	
<input type="checkbox"/>	AlphaNine SD	Grifols	
<input type="checkbox"/>	Alprolix	Biogen Idec	
<input type="checkbox"/>	BeneFIX	Wyeth	
<input type="checkbox"/>	Berinin-P = Berinin HS	CSL Behring	
<input type="checkbox"/>	BETAFACT	LFB	
<input type="checkbox"/>	Christmassin-M	Benesis	
<input type="checkbox"/>	Factor IX Grifols	Grifols	
<input type="checkbox"/>	Faktor IX SDN	Biotest	
<input type="checkbox"/>	Fixnove	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Hemo-B-RAAS	Shanghai RAAS	
<input type="checkbox"/>	Haemonine	Biotest	
<input type="checkbox"/>	Humafactor IX	Kedrion	
<input type="checkbox"/>	Immunine	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	MonoFIX-VF	CSL Bioplasma	
<input type="checkbox"/>	Mononine	CSL Behring	
<input type="checkbox"/>	Nanofix	Octapharma	
<input type="checkbox"/>	Nanotiv	Octapharma	
<input type="checkbox"/>	Nonafact	Sanquin	

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<input type="checkbox"/>	Novact M	Kaketsuken	
<input type="checkbox"/>	Octafix	Octapharma	
<input type="checkbox"/>	Octanine F	Octapharma	
<input type="checkbox"/>	Replenine – VF	BioProducts Lab.	
<input type="checkbox"/>	Other:		

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

22. Prothrombin Complex Concentrates used in 2015

(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
<input type="checkbox"/>	Bebulin VH	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Beriplex P/N	CSL Behring	
<input type="checkbox"/>	Cofact	Sanquin	
<input type="checkbox"/>	Facnyne	Greencross Corp	
<input type="checkbox"/>	Haemosolvex Factor IX	National Bioproducts	
<input type="checkbox"/>	HT DEFIX	SNBTS	
<input type="checkbox"/>	Kanokad Confidex	LFB	
<input type="checkbox"/>	KASKADIL	LFB	
<input type="checkbox"/>	Octaplex	Octapharma	
<input type="checkbox"/>	PPSB-HT	Nihon Pharmaceutical	
<input type="checkbox"/>	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
<input type="checkbox"/>	Profilnine SD	Grifols	
<input type="checkbox"/>	Proplex – T	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Prothrombinex PXT	CSL Bioplasma	
<input type="checkbox"/>	Prothrombinex- VF	CSL Bioplasma	
<input type="checkbox"/>	Prothromplex-T	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Prothroras	Shanghai RAAS	
<input type="checkbox"/>	UMAN Complex D.I.	Kedrion	
<input type="checkbox"/>	Other:		

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

23. Other Products used in 2015

(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
<input type="checkbox"/>	Aryoseven	Aryogen	
<input type="checkbox"/>	Clotafact Wilstart	LFB	
<input type="checkbox"/>	Clottagen (fibrinogen)	LFB	
<input type="checkbox"/>	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
<input type="checkbox"/>	FACTEUR VII	LFB	
<input type="checkbox"/>	Factor VII	Baxalta (Baxter Bioscience)	

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<input type="checkbox"/>	Factor VII	Bio Products	
<input type="checkbox"/>	Factor X P Behring	CSL Behring	
<input type="checkbox"/>	Factor XI	Bio Products	
<input type="checkbox"/>	FEIBA	Baxalta (Baxter Bioscience)	
<input type="checkbox"/>	Fibrinogen HT	Benesis	
<input type="checkbox"/>	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
<input type="checkbox"/>	FIBRORAAS (fibrinogen)	Shanghai RAAS	
<input type="checkbox"/>	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
<input type="checkbox"/>	HEMOLEVEN (Factor XI)	LFB	
<input type="checkbox"/>	NovoSeven (=Niasase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
<input type="checkbox"/>	Riastap	CSL Behring	
<input type="checkbox"/>	Tretten rXIII	NovoNordisk	
<input type="checkbox"/>	WILFACTIN (Von Willebrand Factor)	LFB	
<input type="checkbox"/>	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.**Please return to:**Email: globalsurvey@wfh.org

Fax: 514-875-8916

Address: **World Federation of Hemophilia**

1425 René Lévesque Boulevard West, suite 1010

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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.

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.