November 2014

World Federation of Hemophilia Report on the

ANNUAL GLOBAL SURVEY 2013

50 YEARS OF ADVANCING TREATMENT FOR ALL

WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

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Introduction to the Report on the Annual Global Survey 2013

Report on the Annual Global Survey 2013 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. The purpose of this report is to provide hemophilia organizations, hemophilia treatment centres (HTCs), and health officials with useful information to support efforts to improve or sustain the care of people with bleeding disorders and to assist with program planning. Supplementary charts and graphs using 2013 data can be found on our website.

Methodology

In 1998, the World Federation of Hemophilia (WFH) began collecting information on hemophilia care throughout the world. This survey, called the WFH Annual Global Survey, collects basic demographic information, data on access to care and treatment products, and information on the prevalence (the percentage of the population affected) of infectious complications such as HIV and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization. The 2013 survey is the fourteenth WFH survey. This report uses data for the years 2010, 2011, 2012 and 2013. Not all of our members are able to report every year. A list of participating countries and the last year they provided data can be found on page 13. This report includes data on more than 279,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 107 countries. Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed. The survey questionnaire is included at the end of this report.

Comments on the graphs

The graph showing the increase over time in patients identified contains data from the history of the Annual Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. For all the graphs, answers were not always available for all questions. In such cases, the analysis was done using only data from countries that responded, with the number of respondents as the denominator.

Comments on data collection

Participation in the Annual Global Survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. Some countries are only able to provide detailed data on gender, age, inhibitors and HIV/HCV infection for a limited subset of patients. For example, they may know the total number of people with hemophilia in the country but only have age and gender data from a single treatment centre. This report provides information on the annual usage of treatment products for 2013 only. It includes only those countries where the national hemophilia organization provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations in 2013. The amounts reported may only be factor bought through government and not through other sources. Not all national hemophilia organizations are able to report on all products used in their country. Although factor use per capita is a useful way to compare the availability of treatment products between countries, it is not a reflection of how individual patients are treated. For example, in a country with a lower than expected number of identified patients, the amount of treatment product available per patient is higher than the per capita number would suggest.

Please consider the following caveats about the data in this report.

a) Founder effects can create pockets of patients concentrated geographically. The founder effect occurs when a small population grows in isolation and there is little genetic dilution. This can increase the local frequency of genetic disease compared to the general population. This may occur with hemophilia and all the rare bleeding disorders. In the extremely rare bleeding disorders, consanguinity may lead to an increased incidence in some countries.

b) Countries with small populations can appear to have too many identified patients. Countries submitting data to the WFH range in population from 300,000 to over a billion. With a small denominator (total population), just a few extra identified patients (the numerator) can create the appearance of huge percentage differences between expected and identified patients when really there are only a few more patients than expected.

c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they don't require treatment. In countries with different health care systems, it is likely that patients who do not require treatment will not be identified.

d) Definitions may vary from country to country. Countries may use different definitions to diagnose mild hemophilia and other disorders. In the case of the rare bleeding disorders, some countries may report heterozygous patients while other countries report only patients with bleeding symptoms.

e) Some countries are reporting every patient who seeks treatment while other countries are using methods to identify patients who do not require treatment, such as laboratory screening or follow up with families of identified patients.

f) Data gathering and the state of registries varies. Maintaining accurate registries is time consuming and expensive. It is possible that some registries contain patients who have been double-entered or have died. Even wealthy countries with excellent registries have to carefully review their records to avoid over-counting. Countries with large populations are more susceptible to over-counting. It is harder to keep track of births and deaths. Some patients may be registered in more than one treatment centre and validation of registry data is more difficult.

g) There is also the possibility that the death rate due to HIV and hepatitis C infection is not the same around the world. In some countries there may have been lower infection rates, while other countries may have had better treatment for infected people with hemophilia.

h) The numbers in this report are as reported by our members. They are not independently verified by the WFH. Some countries are not reporting for the whole country; they only have data from certain treatment centres or large cities.

Report on the Annual Global Survey 2013 summary

Demographics

Number of countries in this survey	107
Percentage of world population covered by countries included in 2013 survey report	91%
Number of people identified with hemophilia	176,211
Number of people identified with von Willebrand disease	69,843
Number of people identified with other bleeding disorders	33,774
Total number of people with bleeding disorders identified	279,828
Number of people with hemophilia A	140,313
Number of people with hemophilia B	28,430
Number of hemophilia A patients with clinically identified inhibitors	4,753
Number of hemophilia B patients with clinically identified inhibitors	248

These numbers represent the total number of people identified, not those newly identified in this survey. The total number of patients identified with hemophilia may be higher than the reported sum of people with hemophilia A and B because for some people in some countries, the subtype has not been identified. Some countries included in the report have not surveyed their entire population.

Factor usage

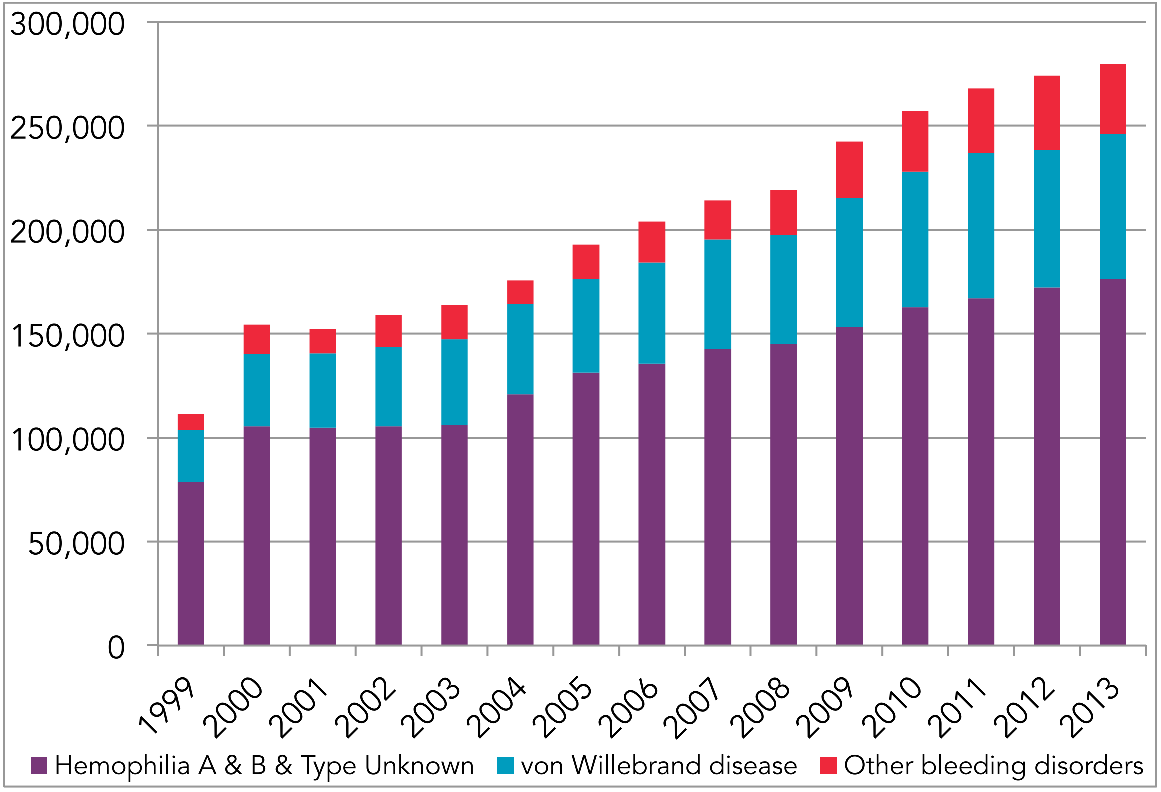
Mean global per capita factor VIII usage	2.06 IU	63 countries
Median global per capita factor VIII usage	0.95 IU	63 countries
Interquartile range (IQR) global per capita factor VIII usage	3.373 IU (0.07 to 3.443)	63 countries
Total reported annual global consumption of factor VIII concentrates	7,610,849,409 IU	63 countries
Mean global per capita factor IX usage	0.36 IU	59 countries
Median global per capita factor IX usage	0.13 IU	59 countries
Interquartile range (IQR) global per capita factor IX usage	0.559 IU (0.013 to 0.572)	59 countries
Total reported annual global consumption of factor IX concentrates	1,267,222,386 IU	59 countries

The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using very little factor, reports one year and not the next, then this will have a significant effect on the mean and median from year to year. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

The chart below shows average per capita factor use for the countries that reported in both the 2012 and 2013 surveys.

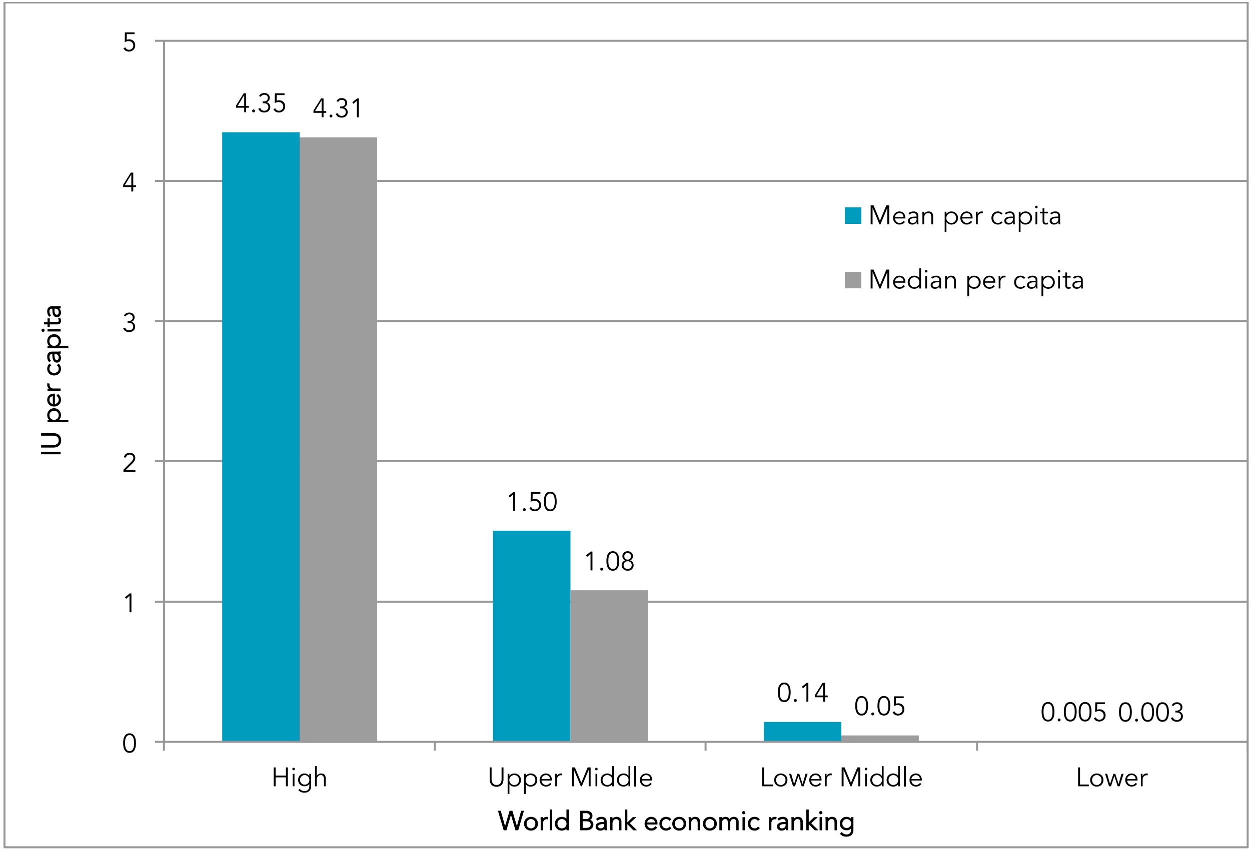
	2012	2013	
Mean global per capita factor VIII usage	**2.19 IU**	**2.20 IU**	*51 countries reporting*
Median global per capita factor VIII usage	**1.02 IU**	**1.00 IU**	*51 countries reporting*
Interquartile range (IQR) global per capita factor VIII usage	**3.664 IU (0.116 to 3.78)**	**3.928 IU (0.07 to 3.998)**	*51 countries reporting*
Mean global per capita factor IX usage	**0.38 IU**	**0.40 IU**	*48 countries reporting*
Median global per capita factor IX usage	**0.18 IU**	**0.20 IU**	*48 countries reporting*
Interquartile range (IQR) global per capita factor IX usage	**0.552 IU (0.007 to 0.559)**	**0.627 IU (0.009 to 0.636)**	*48 countries reporting*

A. Identified patients – all disorders



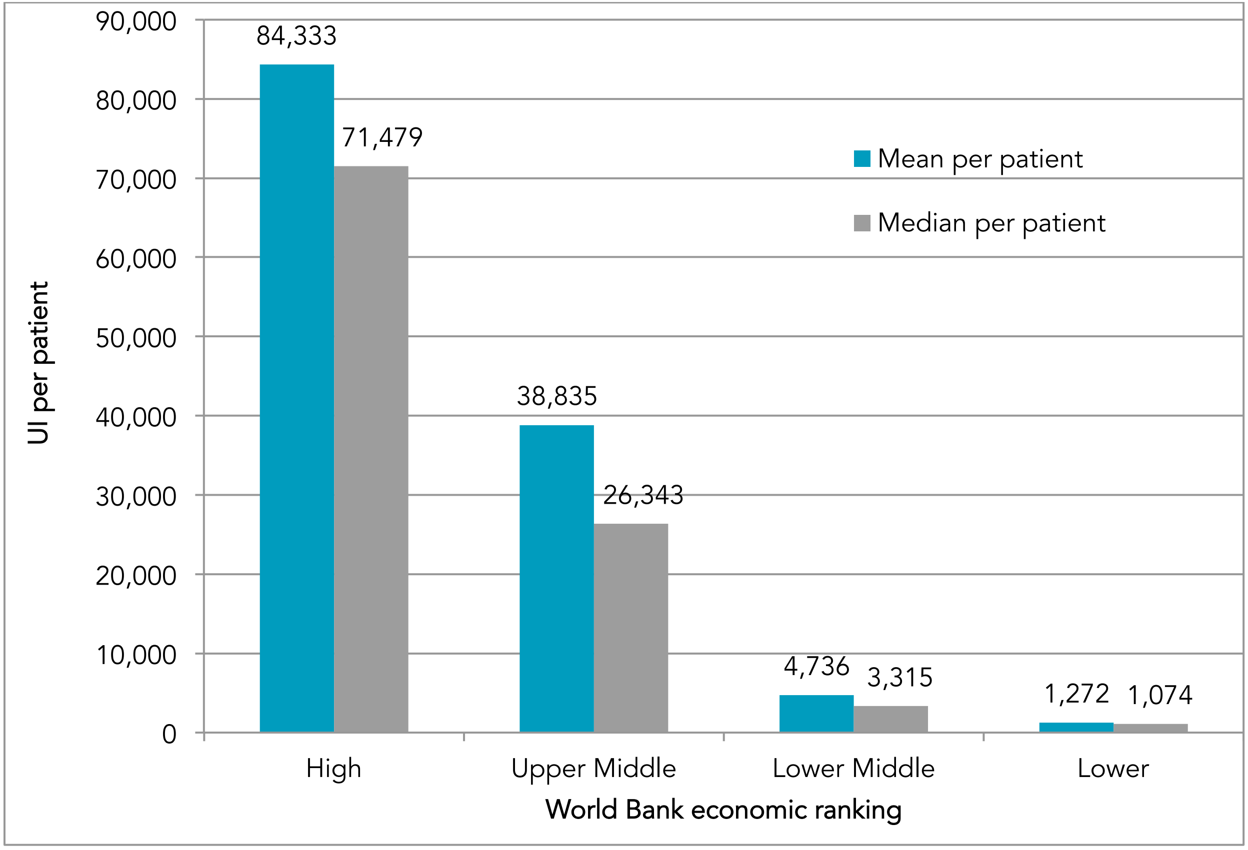
This graph showing the increase over time in patients identified contains data from the history of the Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. For all the graphs, answers are not always available for all questions. In such cases, the graph was created using only data from countries that responded, with the number of respondents as the denominator.

B1. Average global factor VIII use per capita based on World Bank rankings. (Data from 61 countries.)



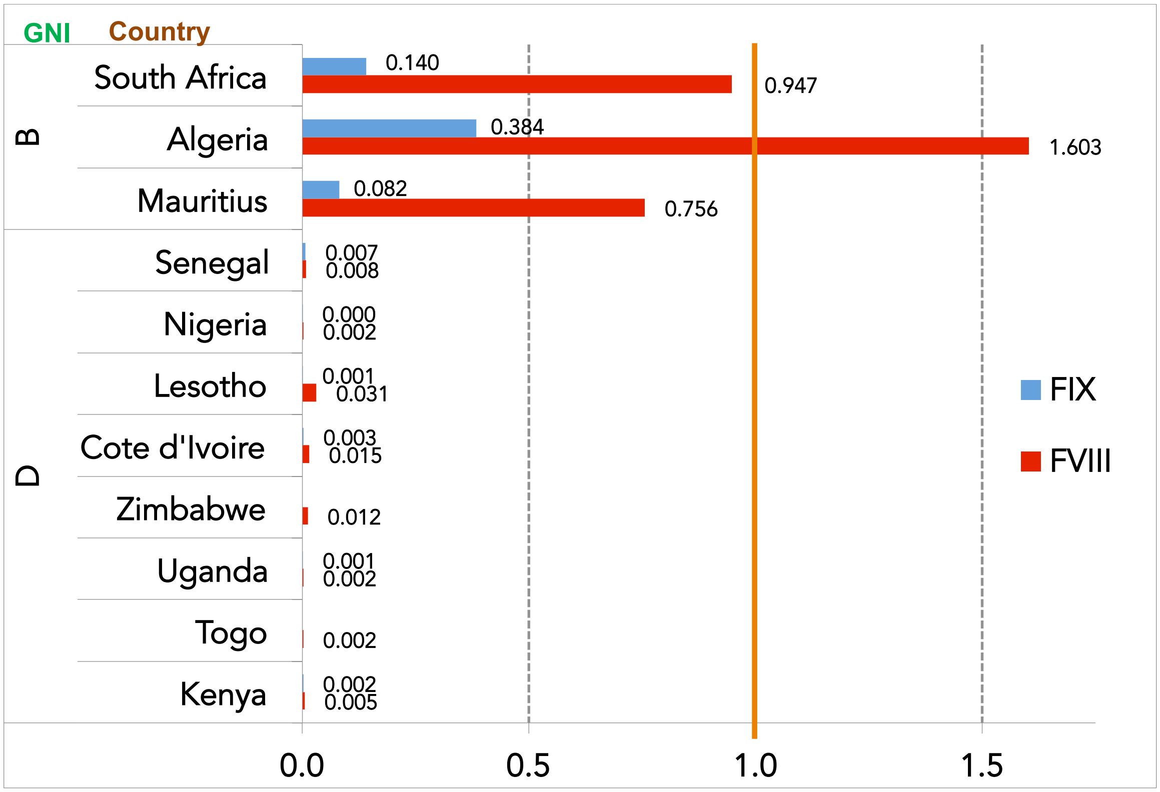
(Gross national income per capita in US dollars: lower income, $0-$1,035; lower middle income, $1,036 - $4,085; upper middle income, $4,086 - $12,615; and high income, $12,616 or more.)

B2. Average global factor VIII use per patient based on World Bank rankings. (Data from 61 countries.)



(Gross national income per capita in US dollars: lower income, $0-$1,035; lower middle income, $1,036 - $4,085; upper middle income, $4,086 - $12,615; and high income, $12,616 or more.)

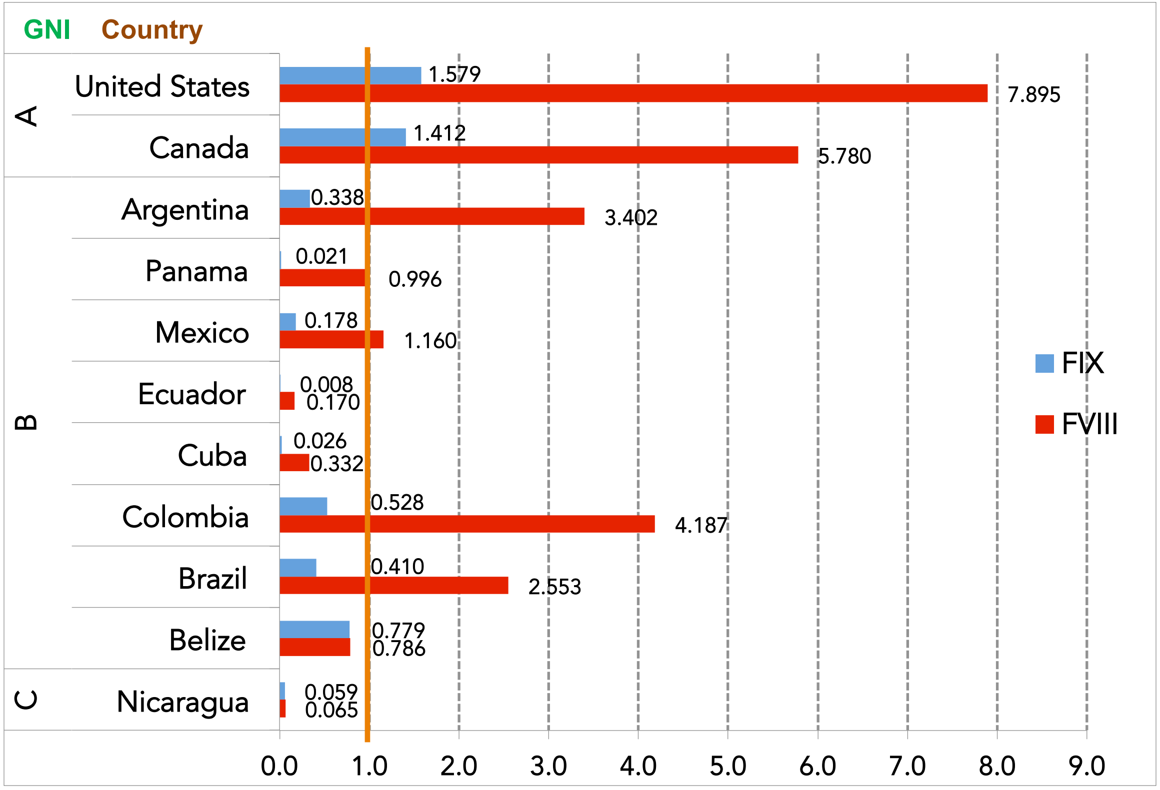
C1. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: **Africa**



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, $0-$1,035; C lower middle income, $1,036 - $4,085; B upper middle income, $4,086 - $12,615; and A high income, $12,616 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX, no data were reported. Only countries that completed the 2013 questionnaire are included in these charts.

C2. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: Americas



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, \$0-\$1,035; C lower middle income, \$1,036 - \$4,085; B upper middle income, \$4,086 - \$12,615; and A high income, \$12,616 or more.) (Regions based on WHO regions.)

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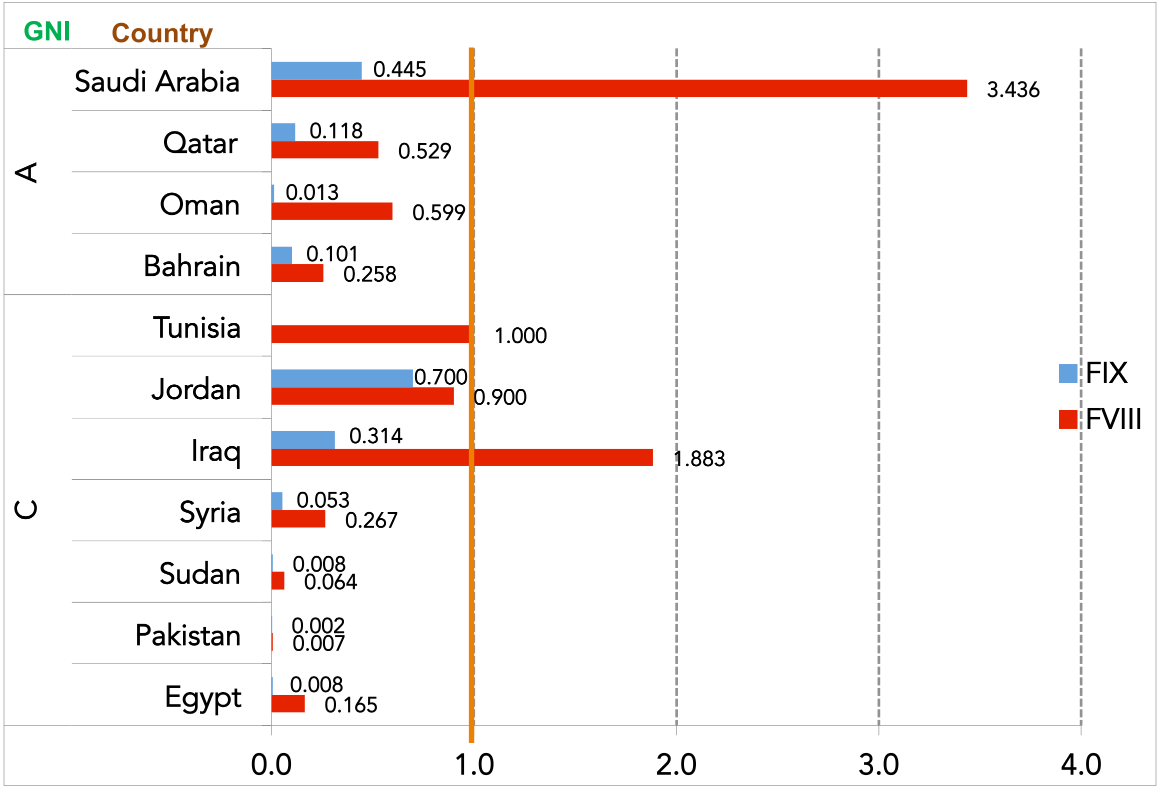
C3. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, $0-$1,035; C lower middle income, $1,036 - $4,085; B upper middle income, $4,086 - $12,615; and A high income, $12,616 or more.) (Regions based on WHO regions.)

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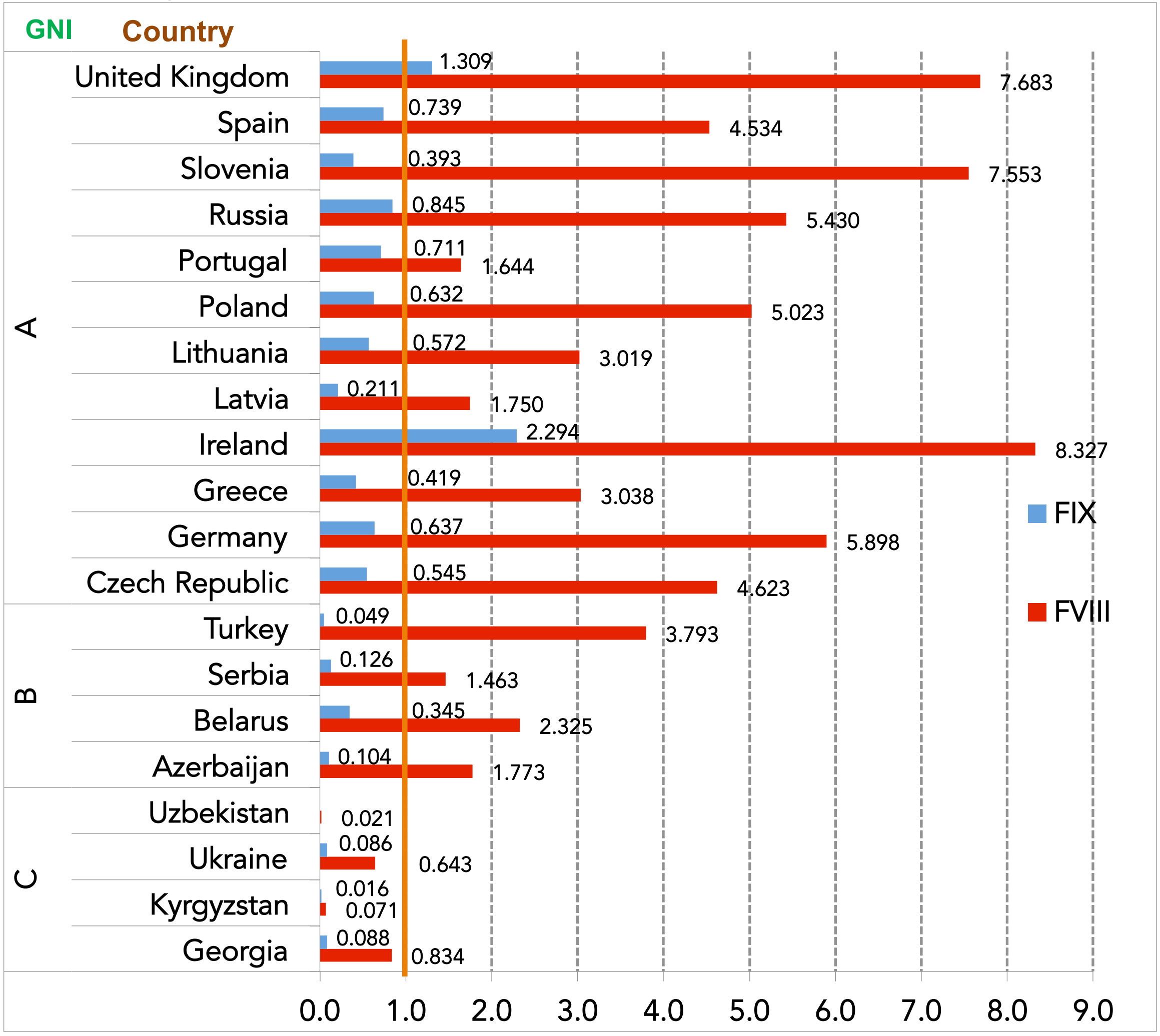
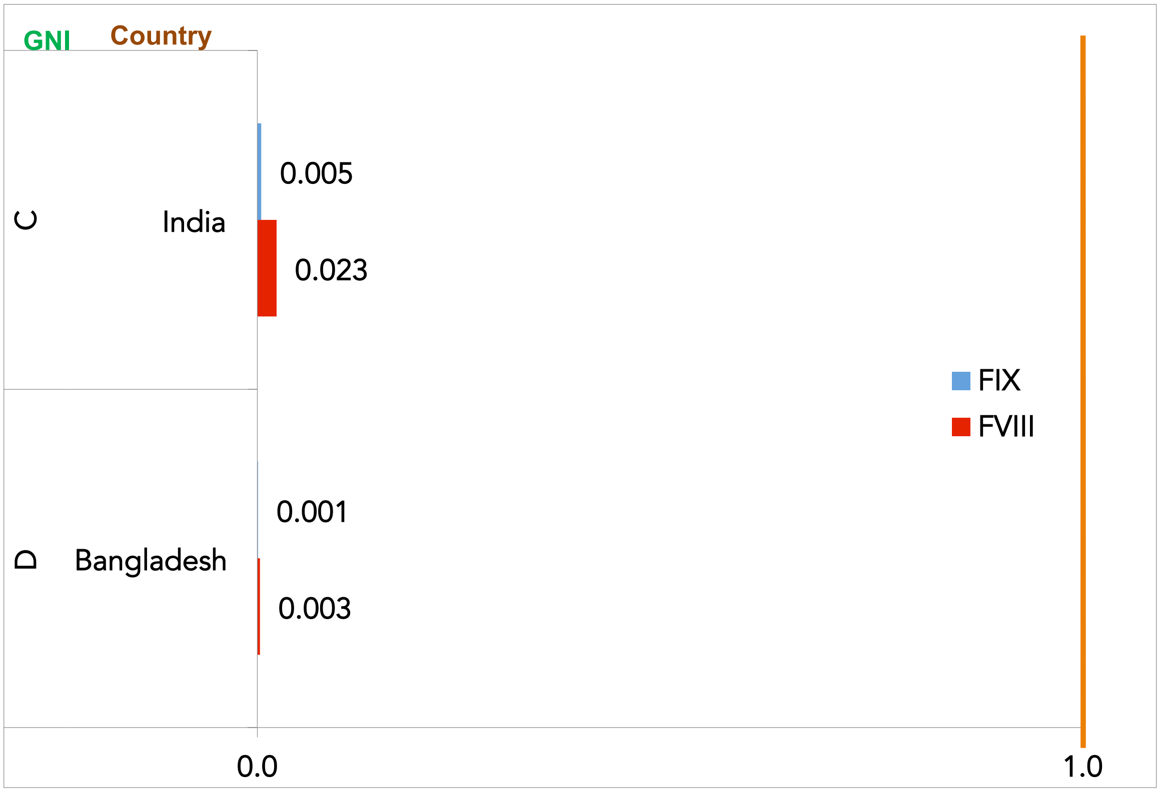
C4. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: Europe



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, $0-$1,035; C lower middle income, $1,036 - $4,085; B upper middle income, $4,086 - $12,615; and A high income, $12,616 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2013 questionnaire are included in these charts.

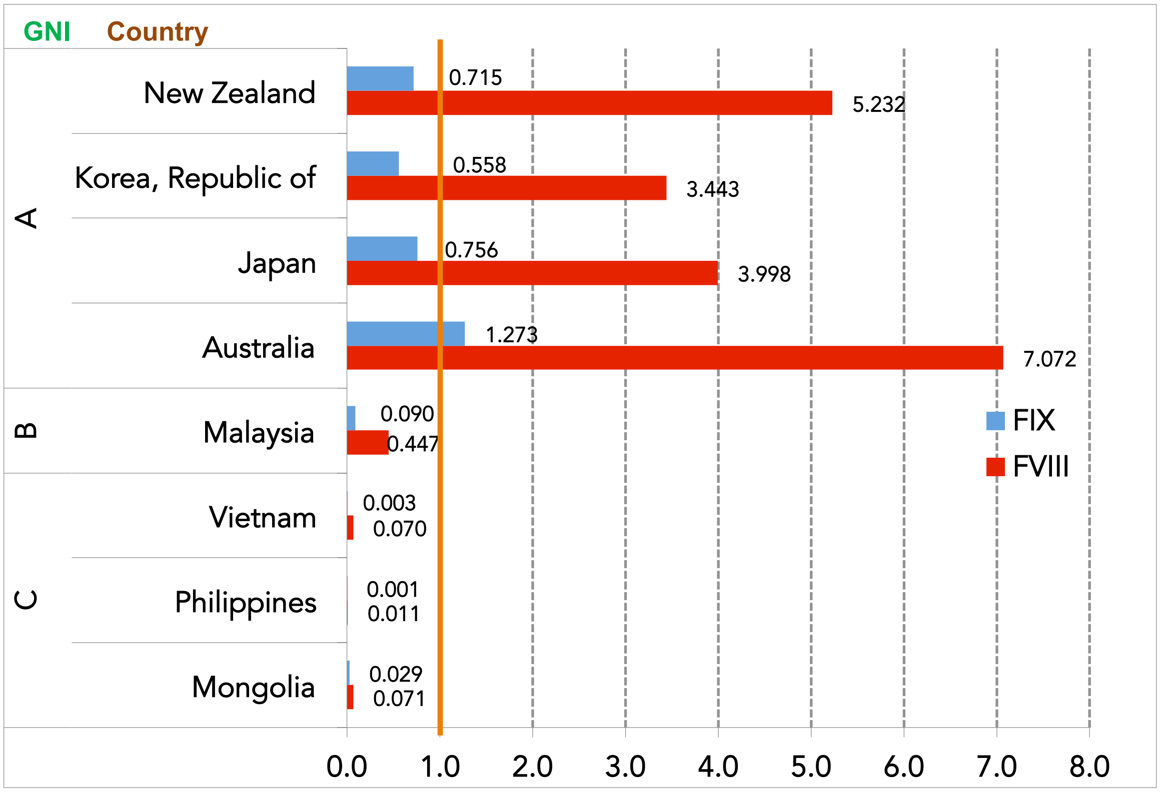
C5. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: **South-East Asia**



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, $0-$1,035; C lower middle income, $1,036 - $4,085; B upper middle income, $4,086 - $12,615; and A high income, $12,616 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2013 questionnaire are included in these charts.

C6. Mean per capita factor VIII and IX use in 2013 – regional and GNI comparisons of IU/total population: **Western Pacific**



Economic category based on World Bank rankings. Categories are based on the rankings for 2013. (GNI in US dollars: D lower income, $0-$1,035; C lower middle income, $1,036 - $4,085; B upper middle income, $4,086 - $12,615; and A high income, $12,616 or more.) (Regions based on WHO regions.)

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Countries included in the Report on the Annual Global Survey 2013

Please note: the year indicates the year the submitted data applies to. Not all of our members are able to submit data every year. For the 2013 survey report, 75 countries submitted data for 2013.

The data used from other years is as follows: 2012: 20 countries, 2011: 9 countries, 2010: 3 countries. All other data are from the year indicated. 2010 to 2012 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2013 only.

Albania	2011
Algeria	2013
Argentina	2013
Australia	2013
Austria	2013
Azerbaijan	2013
Bahrain	2013
Bangladesh	2013
Belarus	2013
Belgium	2013
Belize	2013
Bolivia	2011
Brazil	2013
Bulgaria	2011
Cambodia	2013
Cameroon	2013
Canada	2013
China	2012
Colombia	2013
Costa Rica	2013
Cote d'Ivoire	2013
Cuba	2013
Cyprus	2013
Czech Republic	2013
Denmark	2011
Dominican Republic	2012
Ecuador	2013
Egypt	2013
El Salvador	2012
Eritrea	2012
Ethiopia	2012
Finland	2012
France	2012
Georgia	2013
Germany	2013
Ghana	2013
Greece	2013
Guatemala	2012
Honduras	2012
Hungary	2011
India	2013
Indonesia	2012
Iran	2012
Iraq	2013
Ireland	2013
Israel	2010
Italy	2012
Jamaica	2012
Japan	2013
Jordan	2013
Kenya	2013
Korea, Republic of	2013
Kuwait	2011
Kyrgyzstan	2013
Latvia	2013
Lebanon	2012
Lesotho	2013
Lithuania	2013
Macedonia	2011
Malaysia	2013
Mauritius	2013
Mexico	2013
Moldova	2012
Mongolia	2013
Morocco	2013
Nepal	2013
Netherlands	2012
New Zealand	2013
Nicaragua	2013
Nigeria	2013
Norway	2013
Oman	2013
Pakistan	2013
Palestine	2012
Panama	2013
Peru	2010
Philippines	2013
Poland	2013
Portugal	2013
Qatar	2013
Romania	2011
Russia	2013
Saudi Arabia	2013
Senegal	2013
Serbia	2013
Slovak Republic	2012
Slovenia	2013
South Africa	2013
Spain	2013
Sri Lanka	2010
Sudan	2013
Sweden	2012
Switzerland	2012
Syria	2013
Tanzania	2013
Thailand	2011
Togo	2013
Tunisia	2013
Turkey	2013
Uganda	2013
Ukraine	2013
United Kingdom	2013
United States	2013
Uzbekistan	2013
Venezuela	2013
Vietnam	2013
Zimbabwe	2013

Population statistics

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported, "Not known" means that the member organization reported that they do not know the answer. Countries in **BOLD** reported data for 2013. For countries that did not report population statistics for 2013 but did report during the years 2010-2012, we used the most recent number of patients reported. 2010 to 2012 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2013 only.)

Country	**Population**	**People with hemophilia**	**People with von Willebrand disease**	**People with other bleeding disorders**
Albania	3,011,405	292	2	Not Known
Algeria	38,087,812	2,160	145	518
Argentina	42,610,981	2,469	405	13
Australia	22,262,501	2,570	2,111	725
Austria	8,221,646	647	Not Known	Not Known
Azerbaijan	9,590,159	1,455	220	66
Bahrain	1,281,332	28	Not Known	22
Bangladesh	163,654,860	606	1	3
Belarus	9,625,888	534	172	Not Known
Belgium	10,444,268	1,032	1,677	381
Belize	334,297	15	Not Known	Not Known
Bolivia	10,461,053	96	2	1
Brazil	201,009,622	11,185	5,976	1,702
Bulgaria	6,981,642	618	90	33
Cambodia	15,205,539	88	1	2
Cameroon	20,549,221	129	1	0
Canada	34,568,211	3,704	4,013	1,780
China	1,349,585,838	11,108	58	261
Colombia	45,745,783	1,744	792	243
Costa Rica	4,695,942	209	Not Known	Not Known
Cote d'Ivoire	22,400,835	70	3	3
Cuba	11,061,886	415	198	2,670
Cyprus	1,155,403	99	75	7
Czech Republic	10,162,921	1,060	710	65
Denmark	5,556,452	477	341	87
Dominican Rep.	10,219,630	262	71	123
Ecuador	15,439,429	116	39	3
Egypt	85,294,388	5,050	499	1,068
El Salvador	6,108,590	139	39	21
Eritrea	6,233,682	60	Not Known	Not Known
Ethiopia	93,877,025	61	20	0

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Finland	5,266,114	436	3,016	42
France	65,951,611	6,035	1,496	413
Georgia	4,555,911	272	28	16
Germany	81,147,265	3,967	2,109	Not Known
Ghana	25,199,609	93	2	Not Known
Greece	10,772,967	971	984	322
Guatemala	14,373,472	119	13	1
Honduras	8,448,465	203	3	5
Hungary	9,939,470	Not Known	Not Known	Not Known
India	1,220,800,359	16,456	462	458
Indonesia	251,160,124	1,593	1	Not Known
Iran	79,853,900	5,369	1,212	2,719
Iraq	31,858,481	1,116	259	297
Ireland	4,775,982	850	1,108	1,425
Israel	7,707,042	540	4	1
Italy	61,482,297	4,529	2,233	1,805
Jamaica	2,909,714	Not Known	Not Known	Not Known
Japan	127,253,075	5,769	1,084	344
Jordan	6,482,081	338	240	245
Kenya	44,037,656	556	33	5
Korea, Rep. of	48,955,203	2,004	103	89
Kuwait	2,695,316	Not Known	Not Known	Not Known
Kyrgyzstan	5,548,042	342	8	Not Known
Latvia	2,178,443	157	119	5
Lebanon	4,131,583	165	104	69
Lesotho	1,936,181	24	Not Known	Not Known
Lithuania	3,515,858	167	302	17
Macedonia	2,087,171	315	Not Known	Not Known
Malaysia	29,628,392	1,300	572	266
Mauritius	1,322,238	47	1	7
Mexico	116,220,947	4,776	235	29
Moldova	3,619,925	224	5	5
Mongolia	3,226,516	77	4	2
Morocco	32,649,130	1,123	8	3
Nepal	30,430,267	470	3	14
Netherlands	16,805,037	1,210	2,500	46

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
New Zealand	4,365,113	429	198	32
Nicaragua	5,788,531	225	68	9
Nigeria	174,507,539	168	6	Not Known
Norway	4,722,701	443	887	71
Oman	3,154,134	124	333	325
Pakistan	193,238,868	472	107	72
Palestine	2,676,740	140	Not Known	59
Panama	3,559,408	284	440	45
Peru	29,849,303	743	144	17
Philippines	105,720,644	1,212	31	Not Known
Poland	38,383,809	2,664	1,460	522
Portugal	10,799,270	643	48	17
Qatar	2,042,444	52	33	22
Romania	21,790,479	1,610	348	9
Russia	142,500,482	6,793	1,491	954
Saudi Arabia	26,939,583	391	168	136
Senegal	13,300,410	164	2	7
Serbia	7,243,007	497	259	29
Slovak Republic	5,488,339	577	570	912
Slovenia	1,992,690	210	172	117
South Africa	48,601,098	2,078	615	217
Spain	47,370,542	3,050	Not Known	Not Known
Sri Lanka	21,675,648	664	Not Known	Not Known
Sudan	34,847,910	780	199	216
Sweden	9,119,423	1,014	1,474	332
Switzerland	7,996,026	701	137	88
Syria	22,457,336	627	63	70
Tanzania	48,261,942	64	Not Known	Not Known
Thailand	67,448,120	1,260	69	53
Togo	7,154,237	16	Not Known	Not Known
Tunisia	10,835,873	417	119	252
Turkey	80,694,485	5,188	984	1,765
Uganda	34,758,809	57	2	Not Known
Ukraine	44,573,205	2,188	469	11
United Kingdom	63,395,574	6,821	10,064	5,892
United States	316,668,567	17,073	11,954	1,906

Country	**Population**	**People with hemophilia**	**People with von Willebrand disease**	**People with other bleeding disorders**
Uzbekistan	28,661,637	1,315	93	46
Venezuela	28,459,085	2,506	855	908
Vietnam	92,477,857	2,352	69	216
Zimbabwe	13,182,908	88	Not Known	Not Known
Total	6,461,067,861	176,211	69,843	33,774

Distribution of reported bleeding disorders by country

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported. Countries in **BOLD** reported data for 2013.)

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Albania	254	38		2							1					
Algeria	1,753	407		145	27	10	15	25	242	12	10	9		15		
Argentina	2,151	318	0	405				1	2		2			2		6
Australia	2,071	499	0	2,111	36	0	14	0	54	17	181	17	184	14	4	204
Austria	542	105														
Azerbaijan	1,025	111		220		1	6	16	13	11	2	2	8	1	3	
Bahrain	24	4	0		0	3	2	2	1	5	0	3	0	6		
Bangladesh	514	86	6	1	2	0	0	0	0	0	0	1	0	0	0	0
Belarus	439	95		172												
Belgium	832	193	7	1,677	1	1	23	2	85	6	116	4	34	19	2	88
Belize	10	5														
Bolivia	84	10		2					1				131			
Brazil	9,348	1,837		5,976	64	11	135	23	605	82	148	51		209	52	322
Bulgaria	560	68		90		1			5	3	2	3	8	11		
Cambodia	75	13		1								1		1		
Cameroon	109	10	10	1	0	0	0	0	0	0	0	0	0	0	0	0
Canada	3,006	698		4,013	88	13	61	4	294	39	373	56	50	59	30	713
China	9,675	1,433		58			2		2	1	2	1				
Colombia	1,305	367	72	792	16	9	17	28	52	1	33	24	32	9	2	20
Costa Rica	176	33														
Cote d'Ivoire	64	6	0	3	0	0	0	0	0	2	1	0	0	0	0	0
Cuba	346	69		198	2	1	2	0	0	0	14	7	13	3	0	2,628
Cyprus	43	56		75	3									4		
Czech Rep.	924	136	0	710	0	2	5	0	26	3	17	2	10			
Denmark	384	91		341	1	1	2		4	7	5	11		8	7	43
Dominican Rep.	223	37	123	71					7	22		3	4	3		
Ecuador	110	6	0	39			1	0	0	0	0	1	0	1		
Egypt	4,041	1,009		499	135	8	160	7	99	105	92	32		417	13	
El Salvador	120	19	0	39	0	0	0		2	1	5	0				
Eritrea	54	6														
Ethiopia	51	10	75	20												
Finland	339	97		3,016	3	1	5		10	7	2	13				
France	4,937	1,098	0	1,496	37	1	44	11	135	18	142	25	0			
Georgia	232	40		28					4			2	4	1	1	4
Germany	3,351	616		2,109												
Ghana	72	5	16	2	0	0	0	0	0	0	0	0	0	0	0	0

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Greece	809	162	0	984	13	2	17	0	103	10	85	14		19	14	45
Guatemala	109	10		13					1				1	1		
Honduras	180	23		3					3		1	1				
India	13,448	2,176	832	462	148	9	44	14	37	35	29	68	35	39		
Indonesia	477	66	1,049	1									1			
Iran	4,438	931	0	1,212	107	24	147	190	470	153	152	205	478	467	86	254
Iraq	826	290		259	45	2	8	3	62	17	11	39				110
Ireland	566	284	0	1,108	0	1	134	0	111	117	195	9	0	12	3	273
Israel	458	92		4												
Italy	3,779	750	0	2,233	0	20	132	30	595	96	372	41	59			207
Japan	4,761	1,008		1,084	65	7	32	9	80	20	36	67	28			
Jordan	258	80		240		4	13		46	25	42	12		103	1	
Kenya	470	86		33												5
Korea, Rep. of	1,602	376	26	103	6		5	7	36	2	17	5	11			
Latvia	130	27		119					5							
Lebanon	130	35	0	104	34	0	9	1	7	5	5	2	0	1	0	5
Lesotho	22	2														
Lithuania	146	21		302					11	2		2				
Macedonia	210	105														
Malaysia	1,109	191	0	572	4	3	19	1	47	22	51	18	0	49	1	51
Mauritius	43	4		1					3	1	1					2
Mexico	3,847	588	341	235			2		16	3	2	1	4	1		
Moldova	207	17		5					1		4					
Mongolia	60	17	2	4												
Morocco	752	135	236	8										1		
Nepal	404	69	5	3		1	1		1	7		1				
Netherlands	1,026	184		2,500	0	2	4		9	0	1	11	3	16		
New Zealand	352	77	0	198	2	1	0	0	7	1	3	1	2	2	1	12
Nicaragua	198	27		68	6								1	2		
Nigeria	164	4		6												
Norway	341	102	0	887	2	2	3	0	26	0	1	4	0	10	2	24
Oman	116	8		333	4	1	19	6	58	5	25	1	19	26	2	159
Pakistan	401	71	0	107	3		8	14	13	9		6	1	12	1	5
Palestine	113	27					1			3						56
Panama	253	31	0	440	0	0	0	0	9	16	0	0	0	5	1	16
Peru	577	103	63	144			1		8		5	1		1		0
Philippines	1,012	159	41	31												
Poland	2,280	384		1,460			25	3	227	21	49	12		20	5	160
Portugal	533	110		48	2		3		2	1	7			2		

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Qatar	47	5	0	33					2			3		5		
Romania	1,415	195	15	348		1		2	5		1					
Russia	5,801	992		1,491									954			
Saudi Arabia	310	81	0	168	1	11	6	1	12	4	10	23	0	66	2	0
Senegal	151	13	0	2	0	0	1	0	3	0	0	0				3
Serbia	422	75		259	3			2	13		6	3	1		1	
Slovak Republic	505	72		570	76	0	65	2	640	30	48	3		10	15	23
Slovenia	188	22	0	172	0	0	10	2	15	2	17	1	0	3	0	67
South Africa	1,741	337	0	615	7	0	44	5	19	9	29	8	6	16	25	49
Sri Lanka	498	137	29													
Sudan	667	113	0	199	22		31	0	21	22	2	25	0	90	3	0
Sweden	817	197		1,474		4	1	1	227	20	63	7	1	8	6	250
Switzerland	587	117	0	137	18	0	4	4	29	4	18	14	0	0	0	0
Syria	562	65		63	14		5	28	9	3				11		
Tanzania	34	7	22													
Thailand	294	51		69	1	0	2	1	14	1	0	0	0			
Togo	11	2	3													
Tunisia	327	90		119			11	5	49	5	22	25		80	10	
Turkey	4,369	819		984			29	1	685	141	33	123	723			30
Uganda	37	7	13	2												
Ukraine	1,860	328		469										1		
United Kingdom	5,651	1,170	0	10,064	171	12	161	27	934	208	2,396	64	0	119	72	1,728
United States	12,957	4,022		11,954	130	40	212		804	118	474	128	1,449			
Uzbekistan	1,208	107		93	1	2			8		9			12	1	13
Venezuela	1,982	524		855	19	65	30	27	131	106	346	16	12	15	4	137
Vietnam	1,941	411		69	5	4	4	10	20	12	6	7	45	103		
Zimbabwe	80	8														
Total	140,313	28,430	2,986	69,835	1,324	281	1,737	515	7,277	1,598	5,722	1,239	4,312	2,111	370	7,712

Gender distribution

This table provides the number of males and females with each bleeding disorder for the countries that have that data.

Disorder	Countries reporting	Total patients identified	Male	Percent male	Female	Percent female	Gender not known	Percent not known
Hemophilia A	102	140,313	120,248	86	2,537	2	17,529	12
Hemophilia B	102	28,430	24,534	86	851	3	3,045	11
Hemophilia type unknown	47	2,986	2,606	87	116	4	264	9
Von Willebrand disease	90	69,835	23,996	34	36,937	53	8,902	13
Factor I deficiency	52	1,324	587	44	586	44	151	11
Factor II deficiency	50	281	140	50	125	44	16	6
Factor V deficiency	60	1,737	703	40	845	49	189	11
Factor V+VIII deficiency	51	515	294	57	201	39	20	4
Factor VII deficiency	74	7,277	3,554	49	3,389	47	335	5
Factor X deficiency	63	1,598	754	47	706	44	138	9
Factor XI deficiency	63	5,693	2,484	44	3,005	53	204	4
Factor XIII deficiency	65	1,239	663	54	481	39	95	8
Bleeding disorder: type unknown	50	4,312	1,116	26	602	14	2,594	60
Platelet disorders: Glanzmanns thrombasthenia	57	2,111	730	35	773	37	608	29
Platelet disorders: Bernard Soulier syndrome	38	370	152	41	184	50	34	9
Platelet disorders: other or unknown	42	7,712	2,512	33	4,741	61	459	6

Patients with current clinically significant inhibitors (Patients who do not respond to standard treatment.)

Country	Hemophilia A active inhibitors (total)	Hemophilia A Inhibitors (new cases in 2013)	Hemophilia B active inhibitors (total)	Hemophilia B Inhibitors (new cases in 2013)
Argentina	168	15	8	No data
Australia	169	0	7	0
Austria	20	1	0	0
Azerbaijan	14	2	No data	No data
Bahrain	0	0	0	0
Bangladesh	1	0	0	0
Belarus	43	No data	2	No data
Belize	0	No data	0	No data
Brazil	401	8	31	No data
Cameroon	8	0	0	No data
Canada	90	No data	4	No data
Colombia	105	7	7	0
Costa Rica	20	4	1	0
Cote d'Ivoire	0	0	0	0
Cuba	36	2	0	0
Cyprus	2	1	0	0
Czech Republic	16	3	2	0
Ecuador	0	0	0	0
Egypt	31	3	2	No data
Georgia	7	No data	0	No data
Germany	101	0	5	0
Greece	11	5	2	0
Iraq	70	20	2	1
Ireland	6	2	2	0
Japan	96	No data	20	No data
Jordan	17	No data	1	No data
Korea, Republic of	52	5	8	1
Latvia	2	0	2	0
Lithuania	5	No data	No data	No data
Malaysia	105	12	3	0
Mauritius	0	0	0	0
Mexico	194	No data	12	No data
Morocco	10	2	3	No data
Nepal	2	2	No data	No data
New Zealand	20	2	No data	No data
Nicaragua	2	0	No data	No data
Norway	14	No data	0	0
Oman	20	0	0	0
Pakistan	6	0	0	0
Panama	4	0	0	0

Country	Hemophilia A active inhibitors (total)	Hemophilia A Inhibitors (new cases in 2013)	Hemophilia B active inhibitors (total)	Hemophilia B Inhibitors (new cases in 2013)
Philippines	8	2	1	0
Poland	150	No data	4	No data
Russia	200	0	2	0
Saudi Arabia	42	No data	2	No data
Senegal	5	1	0	0
Serbia	22	0	No data	No data
Slovenia	2	0	0	0
South Africa	164	0	9	0
Sudan	9	0	1	0
Syria	35	No data	1	No data
Ukraine	74	No data	3	No data
United Kingdom	194	33	9	0
United States	895	No data	76	No data
Uzbekistan	35	No data	No data	No data
Venezuela	95	8	3	0
Vietnam	77	28	0	0
Zimbabwe	1	No data	No data	No data
Total	**4,753**	**438**	**248**	**12**

Age distribution: Hemophilia A (72 countries reported age data.)

Country	Hemophilia A	0-4	5-13	14-18	19-44	45+	Age Not Known
Algeria	1,753						100%
Argentina	2,151	5%	17%	10%	45%	21%	3%
Australia	2,071	5%	13%	7%	37%	38%	
Austria	542	3%	12%	7%	44%	33%	
Azerbaijan	1,025	5%	9%	31%	27%	25%	1%
Bahrain	24	21%	17%	17%	42%	4%	
Bangladesh	514	5%	29%	25%	36%	5%	
Belarus	439		20%		7%		73%
Belgium	832	3%	13%	7%	34%	42%	
Belize	10	10%	40%	30%	20%		
Brazil	9,348	6%	17%	12%	49%	16%	0%
Cambodia	75	8%	49%	23%	20%		
Cameroon	109	34%	40%	25%	1%	0%	
Canada	3,006	5%	14%	9%	41%	32%	
China	9,675						100%
Colombia	1,305	10%	23%	12%	33%	13%	10%
Costa Rica	176	5%	23%	13%	47%	13%	
Cote d'Ivoire	64	17%	25%	33%	19%	6%	
Cuba	346	4%	14%	16%	53%	13%	
Czech Republic	924	4%	11%	7%	45%	34%	
Ecuador	110		3%	5%	61%	12%	20%
Egypt	4,041	36%	6%	2%	8%	1%	47%
Georgia	232	14%	17%	11%	48%	10%	
Germany	3,351						100%
Ghana	72	15%	24%	11%	22%	1%	26%
Greece	809	3%	8%	4%	43%	42%	
India	13,448	2%	15%	11%	33%	6%	33%
Iraq	826	22%	37%	19%	20%	3%	
Ireland	566	10%	9%	4%	23%	19%	34%
Japan	4,761						100%
Jordan	258						100%
Kenya	470	28%	30%	15%	10%	13%	5%
Korea, Republic of	1,602	4%	13%	10%	55%	17%	
Latvia	130	9%	12%	5%	47%	25%	2%
Lesotho	22	0%	32%	36%	32%		
Lithuania	146						100%
Malaysia	1,109	26%	21%	5%	8%	2%	37%
Mauritius	43	5%	23%	21%	30%	21%	
Mexico	3,847	3%	17%	12%	42%	9%	18%
Mongolia	60	27%	25%	8%	32%	8%	
Morocco	752	1%	10%	10%	44%	6%	30%
Nepal	404	2%	21%	29%	37%	12%	
New Zealand	352	6%	20%	11%	37%	20%	7%
Nicaragua	198	6%	16%	17%	44%	5%	12%
Nigeria	164	12%	37%	29%	21%	2%	

Country	Hemophilia A	0-4	5-13	14-18	19-44	45+	Age Not Known
Norway	341	6%	16%	6%	39%	33%	
Oman	116	12%	26%	6%	50%	6%	
Pakistan	401	3%	31%	15%	46%	5%	
Panama	253	6%	16%	7%	55%	17%	
Philippines	1,012	5%	23%	18%	38%	6%	11%
Poland	2,280	1%	7%	5%	53%	33%	0%
Portugal	533	2%	10%	7%	44%	30%	9%
Qatar	47	13%	15%	32%	21%		19%
Saudi Arabia	310	25%	39%	18%	19%		
Senegal	151	12%	38%	13%	35%	3%	
Serbia	422	3%	14%	7%	50%	27%	
Slovenia	188	4%	9%	2%	46%	39%	
South Africa	1,741	4%	17%	10%	45%	21%	3%
Sudan	667	14%	32%	17%	34%	3%	
Syria	562	12%	29%	16%	36%	5%	1%
Tanzania	34		29%	3%	32%	3%	32%
Togo	11	18%	36%	9%	36%	0%	
Tunisia	327						100%
Turkey	4,369	6%	22%	14%	45%	14%	
Uganda	37						100%
Ukraine	1,860			25%	75%		
United Kingdom	5,651	6%	13%	8%	38%	34%	0%
United States	12957						100%
Uzbekistan	1,208	4%	24%	20%	49%	4%	
Venezuela	1,982	4%	16%	9%	38%	15%	18%
Vietnam	1,941	8%	13%	9%	26%	6%	39%
Zimbabwe	80	1%	19%	28%	48%	5%	

Age distribution: Hemophilia B (72 countries reported age data)

Country	Hemophilia B	0-4	5-13	14-18	19-44	45+	Age Not Known
Algeria	407						100%
Argentina	318	7%	20%	11%	42%	18%	2%
Australia	499	3%	13%	5%	41%	38%	
Austria	105	3%	16%	13%	34%	33%	
Azerbaijan	111	11%	20%	27%	19%	34%	
Bahrain	4				100%		
Bangladesh	86	8%	36%	29%	24%	2%	
Belarus	95		21%		79%		
Belgium	193	3%	11%	5%	31%	50%	1%
Belize	5		20%	20%	60%		
Brazil	1,837	6%	18%	14%	45%	17%	0%
Cambodia	13	8%	62%		31%		
Cameroon	10	40%	20%	40%			
Canada	698	5%	10%	7%	42%	36%	
China	1,433						100%
Colombia	367	4%	27%	14%	35%	18%	2%
Costa Rica	33	6%	15%	9%	58%	12%	
Cote d'Ivoire	6		17%	33%	33%	17%	
Cuba	69	1%	14%	13%	51%	20%	
Czech Republic	136	7%	11%	7%	38%	38%	
Ecuador	6				100%		
Egypt	1,009	34%	5%	1%	6%	1%	53%
Georgia	40	13%	10%	8%	45%	25%	
Germany	616						100%
Ghana	5	20%	60%		20%		
Greece	162	3%	3%	3%	46%	45%	
India	2,176	3%	14%	12%	35%	8%	28%
Iraq	290	16%	36%	23%	19%	7%	
Ireland	284	5%	13%	28%	32%	21%	
Japan	1,008						100%
Jordan	80						100%
Kenya	86	6%	22%	36%	34%	2%	
Korea, Republic of	376	4%	19%	12%	48%	17%	
Latvia	27	7%	11%	7%	59%	15%	
Lesotho	2	50%	50%				
Lithuania	21						100%
Malaysia	191	37%	25%	4%	17%	2%	16%
Mauritius	4		50%		50%		
Mexico	588	3%	16%	13%	44%	10%	14%
Mongolia	17	35%	24%	12%	24%	6%	
Morocco	135	1%	10%	13%	38%	6%	31%
Nepal	69	29%	7%	30%	26%	7%	
New Zealand	77	6%	9%	5%	43%	30%	6%
Nicaragua	27	7%	7%	11%	59%	7%	7%
Nigeria	4	25%	25%	25%	25%		

Country	**Hemophilia B**	**0-4**	**5-13**	**14-18**	**19-44**	**45+**	**Age Not Known**
Norway	102	7%	17%	9%	33%	34%	
Oman	8	13%	25%	13%	50%		
Pakistan	71	4%	32%	23%	39%	1%	
Panama	31	6%	32%	6%	52%	3%	
Philippines	159	5%	22%	18%	38%	8%	9%
Poland	384	1%	9%	5%	53%	30%	2%
Portugal	110	1%	9%	7%	41%	34%	8%
Qatar	5		20%	40%	20%		20%
Saudi Arabia	81	14%	40%	5%	35%		7%
Senegal	13	23%	54%	8%	8%	8%	
Serbia	75	5%	21%	8%	47%	19%	
Slovenia	22		5%		55%	41%	
South Africa	337	7%	18%	8%	42%	23%	1%
Sudan	113	16%	38%	16%	28%	2%	
Syria	65	3%	34%	23%	35%	2%	3%
Tanzania	7		71%	14%			14%
Togo	2		50%		50%		
Tunisia	90						100%
Turkey	819	7%	23%	14%	44%	13%	
Uganda	7	14%	43%	14%	29%		
Ukraine	328			24%	76%		
United Kingdom	1,170	7%	12%	7%	42%	33%	
United States	4022						100%
Uzbekistan	107	1%	25%	15%	57%	2%	
Venezuela	524	3%	13%	8%	40%	18%	18%
Vietnam	411	7%	10%	6%	25%	4%	42%
Zimbabwe	8	25%	13%		63%		

Age distribution: Hemophilia Type Unknown (14 countries)

Country	Hemophilia Type Unknown	0-4	5-13	14-18	19-44	45+	Age Not Known
Bangladesh	6			100%			
Belgium	7			14%	29%	43%	14%
Cameroon	10	20%	50%	30%			
Colombia	72			3%	21%	35%	42%
Ghana	16	25%	50%	6%	13%		6%
India	832	2%	7%	6%	20%	4%	61%
Korea, Republic of	26	4%	31%	15%	50%		
Mexico	341	1%	8%	4%	22%	3%	63%
Morocco	236	0%	8%	10%	25%	6%	52%
Nepal	5				100%		
Philippines	41		10%	5%	17%	2%	66%
Tanzania	22	9%	64%	9%	5%		14%
Togo	3	100%					
Uganda	13						100%

Age distribution: VWD (64 countries reported age data)

Country	VWD	0-4	5-13	14-18	19-44	45+	Age Not Known
Algeria	145						100%
Argentina	405	0%	4%	3%	49%	30%	14%
Australia	2,111	2%	10%	7%	43%	38%	
Azerbaijan	220	9%	16%	35%	30%	10%	
Bangladesh	1	100%					
Belarus	172						100%
Belgium	1,677	1%	17%	9%	41%	31%	1%
Brazil	5,976	1%	12%	12%	50%	24%	0%
Cambodia	1		100%				
Cameroon	1				100%		
Canada	4,013	1%	10%	9%	48%	32%	
China	58						100%
Colombia	792	2%	19%	29%	21%	5%	24%
Cote d'Ivoire	3				100%		
Cuba	198		7%	19%	49%	24%	
Czech Republic	710	1%	6%	4%	48%	41%	
Ecuador	39		3%	10%	56%	21%	10%
Egypt	499	41%	4%	1%	6%	1%	47%
Georgia	28		11%	4%	61%	25%	
Germany	2,109						100%
Ghana	2						100%
Greece	984	1%	16%	6%	44%	33%	
India	462	3%	15%	11%	39%	5%	27%
Iraq	259	17%	28%	42%	11%	2%	
Ireland	1,108	7%	15%	6%	50%	22%	
Japan	1,084						100%
Jordan	240						100%
Kenya	33	9%	39%	18%	21%		12%
Korea, Republic of	103		11%	17%	57%	15%	
Latvia	119			2%	63%	33%	3%
Lithuania	302						100%
Malaysia	572	12%	26%	8%	35%	5%	14%
Mauritius	1				100%		
Mexico	235	1%	14%	11%	34%	9%	31%
Mongolia	4	25%		50%	25%		
Morocco	8				50%		50%
Nepal	3						100%
New Zealand	198	3%	11%	11%	36%	23%	17%
Nicaragua	68		7%	18%	24%	21%	31%
Nigeria	6			33%	67%		
Norway	887						100%
Oman	333	10%	19%	8%	28%	1%	34%
Pakistan	107	7%	27%	21%	44%	2%	
Panama	440	1%	28%	35%	30%	7%	
Philippines	31		16%	6%	35%		42%

Country	VWD	0-4	5-13	14-18	19-44	45+	Age Not Known
Poland	1,460	1%	11%	10%	51%	25%	2%
Portugal	48		4%	4%	40%	48%	4%
Qatar	33	30%	24%	36%	9%		
Saudi Arabia	168	17%	36%	26%	21%		
Senegal	2		50%	50%			
Serbia	259	1%	10%	5%	57%	26%	
Slovenia	172	1%	10%	8%	52%	29%	
South Africa	615	0%	8%	9%	46%	33%	4%
Sudan	199	19%	43%	17%	19%	3%	
Syria	63	8%	37%	10%	41%	5%	
Tunisia	119						100%
Turkey	984	9%	28%	18%	37%	8%	
Uganda	2	50%	50%				
Ukraine	469			19%	81%		
United Kingdom	10,064	3%	11%	7%	42%	36%	0%
United States	11,954						100%
Uzbekistan	93	4%	18%	12%	57%	9%	
Venezuela	855	2%	17%	8%	39%	18%	16%
Vietnam	69	9%	16%	7%	38%	4%	26%

HIV and HCV infection (People currently living with HIV or HCV. 50 countries.)

Country	Hemophilia HIV+	Hemophilia HCV+	VWD HIV+	VWD HCV+
Algeria	2	27	No data	No data
Argentina	62	619	0	21
Austria	49	194	No data	No data
Azerbaijan	No data	No data	No data	60
Bahrain	0	0	No data	No data
Bangladesh	No data	1	No data	No data
Belarus	0	198	0	No data
Cambodia	1	No data	No data	No data
Cameroon	0	0	0	0
Colombia	4	256	0	20
Costa Rica	13	50	No data	No data
Cote d'Ivoire	0	1	0	0
Cuba	4	146	0	9
Cyprus	2	6	No data	No data
Czech Republic	3	204	0	3
Ecuador	0	0	0	0
Georgia	0	130	0	3
Germany	395	3000	4	No data
Greece	66	333	1	45
India	154	No data	No data	No data

Country	Hemophilia HIV+	Hemophilia HCV+	VWD HIV+	VWD HCV+
Iraq	0	300	0	60
Ireland	32	140	0	11
Japan	734	2443	7	129
Jordan	2	46	No data	No data
Kenya	23	No data	No data	No data
Korea, Republic of	18	198	0	1
Kyrgyzstan	No data	300	No data	No data
Latvia	0	No data	0	No data
Mauritius	0	6	0	1
Mexico	24	118	1	3
Mongolia	0	No data	0	No data
Nepal	1	6	No data	No data
New Zealand	7	46	0	2
Nicaragua	1	17	0	0
Norway	5	No data	0	No data
Oman	2	16	No data	No data
Pakistan	5	110	1	18
Panama	0	0	0	0
Poland	20	No data	No data	No data
Qatar	0	0	0	0
Saudi Arabia	31	88	No data	No data
Serbia	8	126	2	12
Slovenia	7	88	0	6
South Africa	68	222	1	3
Sudan	2	40	No data	No data
Syria	0	71	0	6
United Kingdom	298	577	4	63
Uzbekistan	2	254	No data	13
Venezuela	85	320	9	24
Vietnam	2	237	0	9
Total	2,132	10,934	30	522

Percentage of patients on prophylaxis

For all patients (Hemophilia A and B) that would be eligible for prophylactic treatment based on the protocols in their country.

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Argentina	65%	Estimate	3%	Estimate
Australia	83%	Precise	45%	Precise
Austria	86%	Precise	61%	Precise
Azerbaijan	16%	Estimate	25%	Estimate
Bahrain	100%	Precise	50%	Precise
Belarus	8%	Precise	0%	Precise
Belgium	99%	Estimate	90%	Estimate
Belize	0%	Precise	0%	Precise
Cameroon	0%	Precise	0%	Precise
Colombia	85%	Estimate	40%	Estimate
Costa Rica	23%	Precise	7%	Precise
Cote d'Ivoire	71%	Precise	51%	Precise
Cuba	3%	Precise	0%	Precise
Cyprus	100%	Precise	20%	Estimate
Czech Republic	85%	Precise	38%	Precise
Ecuador	Not known		2%	Precise
Germany	100%	Estimate	50%	Estimate
Ghana	0%	Precise	0%	Precise
Greece	96%	Precise	30%	Estimate
India	1%	Estimate	0%	Estimate
Iraq	100%	Precise	10%	Estimate
Ireland	91%	Precise	60%	Precise
Japan	67%	Estimate	45%	Estimate
Jordan	33%	Estimate	9%	Estimate
Kyrgyzstan	0%	Precise	0%	Precise
Latvia	Not known		56%	Precise
Lithuania	100%	Precise	20%	Estimate
Malaysia	50%	Precise	20%	Precise

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Mauritius	80%	Estimate	1%	Estimate
New Zealand	65%	Estimate	38%	Estimate
Nicaragua	0%	Precise	0%	Precise
Nigeria	0%	Precise	0%	Precise
Norway	100%	Precise	50%	Estimate
Oman	13%	Precise	15%	Precise
Pakistan	10%	Estimate	0%	Precise
Panama	99%	Precise	35%	Precise
Philippines	0%	Precise	0%	Precise
Poland	99%	Estimate	15%	Estimate
Qatar	80%	Precise	80%	Precise
Senegal	60%	Estimate	28%	Estimate
Serbia	40%	Estimate	15%	Estimate
Slovenia	76%	Precise	71%	Precise
South Africa	22%	Estimate	31%	Estimate
Spain	98%	Estimate	25%	Estimate
Sudan	0%	Precise	0%	Precise
Syria	0%	Precise	0%	Precise
Togo	50%	Estimate	50%	Estimate
Turkey	80%	Estimate	75%	Estimate
Uganda	0%	Precise	0%	Precise
Ukraine	30%	Estimate	0%	Estimate
United Kingdom	95%	Estimate	70%	Estimate
United States	82%	Estimate	43%	Estimate
Venezuela	40%	Precise	20%	Precise
Vietnam	0%	Estimate	0%	Estimate
Zimbabwe	1%	Precise	0%	Precise

Reported Use of Factor Concentrates in 2013: Factor VIII

The quantities of factor VIII in this chart are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2013 while others report the amount *purchased*. The per capita number divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients. Please note that some FVIII products are used in the treatment of von Willebrand disease and not for hemophilia A.

Country	**Factor VIII total IU**	**Factor VIII plasma-derived**	**Factor VIII recombinant**	**Factor VIII humanitarian aid**	**Factor VIII per capita**	**FVIII per cap. without hum. aid**	**Total percent plasma-derived**	**Total percent recombinant**
Algeria	61,065,000	47,115,500	13,949,500	0	1.603	1.603	77%	23%
Argentina	144,965,000	108,665,000	36,300,000	265,000	3.402	3.396	75%	25%
Australia	157,449,750	18,324,250	139,125,500	0	7.072	7.072	12%	88%
Azerbaijan	17,000,000	*No data*	288,000	*No data*	1.773			2%
Bahrain	330,000	0	330,000	0	0.258	0.258	0%	100%
Bangladesh	461,234	404,234	57,000	286,234	0.003	0.001	88%	12%
Belarus	22,378,000	22,378,000	0	0	2.325	2.325	100%	0%
Belize	262,599	81,360	181,239	262,599	0.786	0	31%	69%
Brazil	513,256,350	460,689,850	52,566,500	0	2.553	2.553	90%	10%
Canada	199,787,624	0	199,787,624	0	5.780	5.780	0%	100%
Colombia	191,539,000	106,286,000	85,253,000	93,500	4.187	4.185	55%	45%
Cote d'Ivoire	330,371	20,041	310,330	330,371	0.015	0	6%	94%
Cuba	3,676,429	3,488,105	188,324	191,429	0.332	0.315	95%	5%
Czech Republic	46,984,270	27,855,215	19,129,055	0	4.623	4.623	59%	41%
Ecuador	2,620,500	*No data*	0	*No data*	0.170			0%
Egypt	14,110,000	14,110,000	0	110,000	0.165	0.164	100%	0%
Georgia	3,800,000	3,750,000	50,000	0	0.834	0.834	99%	1%
Germany	478,570,322	192,373,950	286,196,372	0	5.898	5.898	40%	60%
Greece	32,723,500	2,164,000	30,559,500	0	3.038	3.038	7%	93%
India	28,000,000	27,000,000	1,000,000	0	0.023	0.023	96%	4%
Iraq	60,000,000	0	60,000,000	0	1.883	1.883	0%	100%
Ireland	39,770,400	1,199,650	38,570,750	0	8.327	8.327	3%	97%
Japan	508,700,000	90,700,000	418,000,000	0	3.998	3.998	18%	82%
Jordan	5,833,873	*No data*	*No data*	*No data*	0.900			
Kenya	200,000	175,000	25,000	200,000	0.005	0	88%	12%
Korea, Rep. of	168,552,000	51,500,000	117,052,000	0	3.443	3.443	31%	69%
Kyrgyzstan	393,750	325,750	68,000	0	0.071	0.071	83%	17%
Latvia	3,811,750	2,788,500	1,023,250	0	1.750	1.750	73%	27%
Lesotho	60,000	*No data*	*No data*	*No data*	0.031			
Lithuania	10,613,000	6,199,500	4,413,500	*No data*	3.019		58%	42%
Malaysia	13,249,750	12,937,250	312,500	0	0.447	0.447	98%	2%
Mauritius	1,000,000	1,000,000	0	0	0.756	0.756	100%	0%
Mexico	134,860,788	119,208,750	15,652,038	80,500	1.160	1.160	88%	12%
Mongolia	230,500	130,500	*No data*	100,000	0.071	0.040	57%	
New Zealand	22,840,000	3,021,000	19,819,000	0	5.232	5.232	13%	87%

Country	**Factor VIII total IU**	**Factor VIII plasma-derived**	**Factor VIII recombinant**	**Factor VIII humanitarian aid**	**Factor VIII per capita**	**FVIII per cap. without hum. aid**	**Total percent plasma-derived**	**Total percent recombinant**
Nicaragua	375,000	375,000		375,000	0.065	0	100%	
Nigeria	293,282	*No data*	*No data*	293,282	0.002	0		
Oman	1,890,000	*0*	1,890,000	0	0.599	0.599		100%
Pakistan	1,320,752	245,690	1,075,062	1,056,602	0.007	0.001	19%	81%
Panama	3,543,750	3,518,750	25,000	0	0.996	0.996	99%	1%
Philippines	1,192,906	593,870	599,036	305,906	0.011	0.008	50%	50%
Poland	192,792,100	187,444,600	5,347,500	*No data*	5.023		97%	3%
Portugal	17,750,000	13,095,000	4,655,000	*No data*	1.644		74%	26%
Qatar	1,080,000	20,000	1,060,000	*No data*	0.529		2%	98%
Russia	773,844,041	663,688,323	110,155,718	0	5.430	5.430	86%	14%
Saudi Arabia	92,575,000	36,225,000	56,350,000	0	3.436	3.436	39%	61%
Senegal	100,150	0	100,150	100,150	0.008	0	0%	100%
Serbia	10,593,500	10,193,500	400,000	0	1.463	1.463	96%	4%
Slovenia	15,050,905	3,915,855	11,135,050	0	7.553	7.553	26%	74%
South Africa	46,008,800	46,008,800		0	0.947	0.947	100%	
Spain	214,773,669	133,159,675	81,613,994	0	4.534	4.534	62%	38%
Sudan	2,237,490	2,107,500	129,990	129,990	0.064	0.06	94%	6%
Syria	6,000,000	6,000,000		255,000	0.267	0.256	100%	
Togo	11,819	*No data*	*No data*	11,819	0.002	0		
Tunisia	10,835,873	*No data*	*No data*	*No data*				
Turkey	306,111,000	238,754,750	67,356,250	*No data*	3.793		78%	22%
Uganda	70,409	19,644	50,765	70,409	0.002	0	28%	72%
Ukraine	28,657,760	27,190,507	1,467,253	0	0.643	0.643	95%	5%
United Kingdom	487,073,786	50,612,550	436,461,236	0	7.683	7.683	10%	90%
United States	2,500,000,000	350,000,000	2,150,000,000	0	7.895	7.895	14%	86%
Uzbekistan	600,000	600,000		493,000	0.021	0.004	100%	
Vietnam	6,477,000	6,477,000	0	124,000	0.070	0.069	100%	0%
Zimbabwe	164,657	164,657	*No data*	164,657	0.012	0	100%	
Total	7,610,849,409	3,104,302,076	4,470,079,986	5,323,123			41%	59%

Reported Use of Factor Concentrates in 2013: Factor IX

The quantities of factor IX in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2013 while others report the amount *purchased*. The factor IX per capita divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients.

Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Algeria	14,609,700	14,609,700		0	0.384	0.384	100%	
Argentina	14,400,000	10,500,000	3,900,000	*No data*	0.338		73%	27%
Australia	28,348,750	2,604,000	25,744,750	0	1.273	1.273	9%	91%
Azerbaijan	1,000,000	*No data*	*No data*	*No data*	0.104			
Bahrain	130,000	130,000		0	0.101	0.101	100%	
Bangladesh	125,000	125,000	0	125,000	0.001	0.000	100%	0%
Belarus	3,324,000	3,324,000	0	0	0.345	0.345	100%	0%
Belize	260,536	0	260,536	260,536	0.779	0.000	0%	100%
Brazil	82,433,100	82,433,100		0	0.410	0.410	100%	
Canada	48,801,230	5,872,346	42,928,884	0	1.412	1.412	12%	88%
Colombia	24,168,000	17,003,000	7,165,000	23,558	0.528	0.528	70%	30%
Cote d'Ivoire	60,000	0	60,000	60,000	0.003	0.000	0%	100%
Cuba	283,000	283,000	0	*No data*	0.026		100%	0%
Czech Republic	5,539,509	4,547,576	991,933	0	0.545	0.545	82%	18%
Ecuador	121,800	*No data*	0	*No data*	0.008			0%
Egypt	650,000	150,000	500,000	50,000	0.008	0.007	23%	77%
Georgia	400,000	400,000	0	*No data*	0.088		100%	0%
Germany	51,674,950	35,006,500	16,668,450	0	0.637	0.637	68%	32%
Greece	4,515,410	405,910	4,109,500	0	0.419	0.419	9%	91%
India	6,110,000	6,110,000	0	50,000	0.005	0.005	100%	0%
Iraq	10,000,000	0	10,000,000	0	0.314	0.314	0%	100%
Ireland	10,953,750	0	10,953,750	0	2.294	2.294	0%	100%
Japan	96,300,000	45,600,000	50,700,000	0	0.756	0.756	47%	53%
Jordan	4,537,457	*No data*	*No data*	*No data*	0.700			
Kenya	80,000	0	80,000	80,000	0.002	0.000	0%	100%
Korea, Rep. of	27,299,000	4,240,000	23,059,000	0	0.558	0.558	16%	84%
Kyrgyzstan	91,500	86,500	5,000	0	0.016	0.016	95%	5%
Latvia	460,500	460,500	0	0	0.211	0.211	100%	0%
Lesotho	1,000	*No data*	*No data*	*No data*	0.001			
Lithuania	2,011,100	2,011,100	0	*No data*	0.572		100%	0%
Malaysia	2,664,000	2,651,500	12,500	0	0.090	0.090	100%	0%
Mauritius	108,000	108,000	0	0	0.082	0.082	100%	0%
Mexico	20,685,700	20,685,700	0	17,100	0.178	0.178	100%	0%

Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Mongolia	92,000	42,000	*No data*	50,000	0.029	0.013	46%	
New Zealand	3,122,000	1,262,000	1,860,000	0	0.715	0.715	40%	60%
Nicaragua	342,000	342,000		342,000	0.059	0.000	100%	
Nigeria	50,000	*No data*	*No data*	50,000	0.000	0.000		
Oman	40,000		40,000	0	0.013	0.013		100%
Pakistan	427,000	191,000	236,000	427,000	0.002	0.000	45%	55%
Panama	73,200	73,200		*No data*	0.021		100%	
Philippines	144,065	16,065	128,000	144,065	0.001	0.000	11%	89%
Poland	24,258,950	23,604,200	654,750	*No data*	0.632		97%	3%
Portugal	7,676,000	4,680,000	2,996,000	*No data*	0.711		61%	39%
Qatar	240,000	0	240,000	*No data*	0.118		0%	100%
Russia	120,396,002	120,396,002	0	0	0.845	0.845	100%	0%
Saudi Arabia	12,000,000	7,000,000	5,000,000	0	0.445	0.445	58%	42%
Senegal	95,000	0	95,000	95,000	0.007	0.000	0%	100%
Serbia	915,500	915,500	0	0	0.126	0.126	100%	0%
Slovenia	783,500	783,500	0	0	0.393	0.393	100%	0%
South Africa	6,819,500	6,819,500		0	0.140	0.140	100%	
Spain	35,000,000	12,500,000	22,500,000	0	0.739	0.739	36%	64%
Sudan	261,500	261,500	0	0	0.008	0.008	100%	0%
Syria	1,200,000	1,200,000		100,000	0.053	0.049	100%	
Turkey	3,992,700	3,992,700	0	*No data*	0.049		100%	0%
Uganda	46,916	44,410	2,506	46,916	0.001	0.000	95%	5%
Ukraine	3,836,649	3,836,649	0	0	0.086	0.086	100%	0%
United Kingdom	82,965,912	9,999,705	72,966,207	0	1.309	1.309	12%	88%
United States	500,000,000	100,000,000	400,000,000	0	1.579	1.579	20%	80%
Vietnam	297,000	297,000	0	0	0.003	0.003	100%	0%
Total	1,267,222,386	557,604,363	703,857,766	1,970,475			44%	56%

A. National Hemophilia Organization

Organization name	
City	
Country	
Phone	
E-mail	
This form completed by:	First name Last name Email

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** ☐ A **registry** of all PWH and other inherited bleeding disorders in your country. ☐ A **registry** of all PWH and other inherited bleeding disorders in your country's hemophilia treatment centres. ☐ Count information provided by all of your country's hemophilia treatment centres ☐ Count information provided by some of your country's hemophilia treatment centres. ☐ Other (Describe):
Is your database updated throughout the year or only once per year?	☐ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
Who updates the database?	☐ Doctors update the database ☐ Patient organization updates the database ☐ Hospitals or clinics update the database ☐ Other (please describe):

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)		☐
2. Number of identified people with **von Willebrand disease** (VWD)		☐
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.)		☐
Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

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				
5 - 13 years old				
14 - 18 years old				
19 - 44 years old				
45 years or older				
Patients with age Unknown				
No age data	☐	☐	☐	☐

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

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					☐
Hemophilia B					☐
Hemophilia, type unknown					☐
von Willebrand disease					☐
Factor I deficiency					☐
Factor II deficiency					☐
Factor V deficiency					☐
Factor V+VIII deficiency					☐
Factor VII deficiency					☐
Factor X deficiency					☐
Factor XI deficiency					☐
Factor XIII deficiency					☐
Rare factor deficiency: type unknown					☐
Platelet disorders: Glanzmann's thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

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

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

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

Factor level measurements ☐	Clinical diagnosis ☐ (bleeding, family history)	Other ☐ (please describe):	No data ☐

How are patients with von Willebrand Disease classified?

Factor level measurements ☐	Severe bleeding symptoms ☐	Other ☐ (please describe):	No data ☐

8. Number of identified people with hemophilia by diagnosis of 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 per cent of the normal level of clotting factor is no different from a man with the same factor levels—she has hemophilia.

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					☐
Hemophilia A female					☐
Hemophilia B male					☐
Hemophilia B female					☐

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 ☐	Not sure ☐

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**
			☐

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

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 2013**	**No Data**
Hemophilia A			☐
Hemophilia B			☐

11. Products used to treat hemophilia: How many patients were treated with the following products? (Please note: we are asking for a number, not a percentage.)

Treatment product	Number treated	Product is available	Product is used	Product is not used
Plasma		☐	☐	☐
Cryoprecipitate		☐	☐	☐
Plasma-derived concentrate		☐	☐	☐
Recombinant concentrate		☐	☐	☐
DDAVP (Desmopressin)		☐	☐	☐

12. Products used to treat VWD: How many patients were treated with the following products? (Please note: we are asking for a number, not a percentage.)

Treatment product	Number treated	Product is available	Product is used	Product is not used
Plasma		☐	☐	☐
Cryoprecipitate		☐	☐	☐
Plasma-derived concentrate		☐	☐	☐
DDAVP (Desmopressin)		☐	☐	☐

13. HIV and hepatitis C infection among living people with hemophilia (Please note: we are asking for a number, not a percentage.)

Infectious Disease	**Number of people infected**	**Number of people tested**	**No Data**
HIV			☐
Hepatitis C			☐

14. HIV and hepatitis C infection among living people with von Willebrand disease (Please note: we are asking for a number, not a percentage.)

Infectious Disease	**Number of people infected**	**Number of people tested**	**No Data**
HIV			☐
Hepatitis C			☐

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2013)

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			
HIV			
Liver disease			
Other causes			

C. Hemophilia Care System in Your Country

A Hemophilia Treatment Centre (HTC) is a medical centre providing basic diagnosis and treatment for inherited bleeding disorders.

A Hemophilia Comprehensive Care Centre (HCCC) is a medical centre providing a full range of facilities for the diagnosis and management of inherited bleeding disorders.

16. How many **hemophilia treatment centres** are there in your country?	

How many **hemophilia comprehensive care centres** are there in your country?	
Percentage of hemophilia patients with access to hemophilia treatment centres:	

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 eligible children (under age 18) **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What percentage of eligible adults (over age 18) **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐

D. The Cost and Use of Factor Concentrates

18. Annual usage of factor concentrates	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2013?		☐		☐
How many international units of **plasma-derived** concentrates were used in your country in 2013?		☐		☐
How many international units of **recombinant** concentrates were used in your country in 2013?		☐		☐

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

Of the number reported above how many international units were **humanitarian aid**?		☐		☐

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

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:

19. Factor VIII Concentrates used in 2013

(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	Baxter Bioscience	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Beriate P	CSL Behring	
☐	BIOSTATE	CSL Bioplasma	
☐	Conco-eight-HT	Benesis	
☐	Confact F	Kaketsuken	
☐	Cross Eight M	Japanese Red Cross	
☐	Emoclot D.I.	Kedrion	
☐	FACTANE	LFB	
☐	Factor 8 Y	BioProducts Lab.	
☐	Faktor VIII SDH Intersero	Intersero	
☐	Fanhdi	Grifols	
☐	GreenEight	GreenCross	
☐	GreenGene	GreenCross	
☐	GreenMono	Greencross Corp	
☐	Haemate P (= Haemate HS)	CSL Behring	
☐	Haemoctin SDH	Biotest	
☐	Haemosolvate Factor VIII	National Bioproducts	
☐	Helixate NexGen = Helixate FS	CSL Behring	
☐	Hemofil M AHF	Baxter BioScience	
☐	HEMORAAS SD plus H	Shanghai RAAS	
☐	HEMORAAS-HP, SD plus H	Shanghai RAAS	
☐	HEMORAAS-IP, SD plus H	Shanghai RAAS	
☐	Humate P	CSL Behring	
☐	Humafaktor 8	Human BioPlazma	
☐	Immunate	Baxter BioScience	
☐	Koate DVI	Talecris	
☐	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
☐	Monoclate P	CSL Behring	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Optivate	Bio Products Laboratory	
☐	Recombinate rAHF	Baxter BioScience	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	

☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

20. Factor IX Concentrates used in 2013

(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	
☐	BeneFIX	Wyeth	
☐	Berinin-P = Berinin HS	CSL Behring	
☐	BETAFACT	LFB	
☐	Christmassin-M	Benesis	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Immunine	Baxter BioScience	
☐	MonoFIX-VF	CSL Bioplasma	
☐	Mononine	CSL Behring	
☐	Nanotiv	Octapharma	
☐	Nonafact	Sanquin	
☐	Novact M	Kaketsuken	
☐	Octanine F	Octapharma	
☐	Replenine – VF	BioProducts Lab.	
☐	Other:		

21. Prothrombin Complex Concentrates used in 2013

(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
☐	Bebulin VH	Baxter BioScience	
☐	Beriplex P/N	CSL Behring	
☐	Cofact	Sanquin	
☐	Facnyne	Greencross Corp	
☐	Haemosolvex Factor IX	National Bioproducts	
☐	HT DEFIX	SNBTS	
☐	KASKADIL	LFB	
☐	Octaplex	Octapharma	
☐	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
☐	Profilnine SD	Grifols	

☐	Proplex – T	Baxter BioScience	
☐	Prothrombinex- VF	CSL Bioplasma	
☐	Prothromplex-T	Baxter BioScience	
☐	Prothroraas	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

22. Other Products used in 2013

(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
☐	Clottagen (fibrinogen)	LFB	
☐	Fibrinogen HT	Benesis	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
☐	Riastap	CSL Behring	
☐	Factor VII	Baxter BioScience	
☐	Factor VII	Bio Products	
☐	FACTEUR VII	LFB	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	HEMOLEVEN (Factor XI)	LFB	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	FEIBA	Baxter	
☐	NovoSeven (=Niastase) (activated factor VII)	NovoNordisk	Price: Vial size:
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price: Vial size:
☐	Other:		

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.

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL

WORLD FEDERATION OF HEMOPHILIA
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