December 2012

World Federation of Hemophilia Report on the

ANNUAL GLOBAL SURVEY 2011

WFH 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 WFH Global Survey 2011

Report on the Annual Global Survey 2011 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 useful information to hemophilia organizations, hemophilia treatment centres (HTCs), and health officials involved in efforts to reduce or prevent complications of bleeding disorders in order to assist with program planning.

Methodology

In 1998, the World Federation of Hemophilia (WFH) began collecting information on hemophilia care throughout the world. This survey, called the WFH Global Survey, collects basic demographic information, data on resources of 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 2011 survey is the twelfth WFH survey. This report uses data for the years 2007, 2008, 2009, 2010 and 2011. Not all of our members are able to report every year. A list of participating countries and their data year can be found on page 10. The survey includes data on more than 265,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 108 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 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 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. Countries that are part of the WFH's Global Alliance for Progress (GAP) program (Azerbaijan, Belarus, Ecuador, Jordan, Lebanon, Mexico, Russia, Thailand, Tunisia, China, and Syria) report more frequently than once per year, in cases where a 2011 survey form was not completed other WFH data was used. 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 have age and gender data from just one treatment centre. This report provides information on the annual usage of treatment products for 2011 only. It includes only those countries where the national hemophilia organization provided information. Quantities reported used were not independently verified except when the WFH has data on humanitarian donations in 2011. The amounts reported may only be factor bought through government or other sources. Not all national hemophilia organizations are able to report on all product used in their country.

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 that 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 that 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 big 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, 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 for their countries. 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.

2011 WFH Global Survey summary

Demographics

Number of countries in this survey	**108**
Percentage of world population covered by countries in 2011 survey report	**90.6%**
Number of people identified with hemophilia*	**167,110**
Number of people identified with VWD	**69,729**
Number of people identified with other bleeding disorders	**31,191**
Total number of people with bleeding disorders identified	**268,030**
Number of people with hemophilia A	**134,354**
Number of people with hemophilia B	**26,821**
Number of hemophilia A patients with clinically identified inhibitors	3387
Number of hemophilia B patients with clinically identified inhibitors	183

* Please note that the total number of patients identified with hemophilia may be higher than the number of patients identified with specific types of hemophilia because some patients in some countries are known to have bleeding disorders but the specific diagnosis has not been reported.

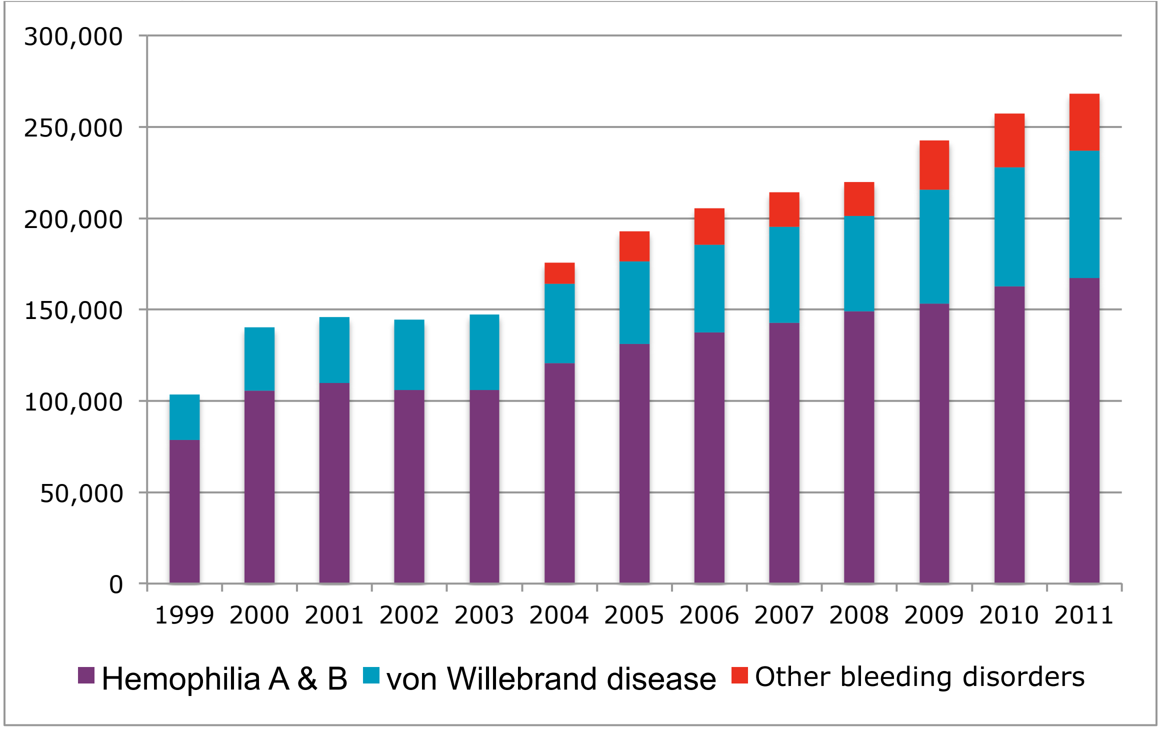
Factor usage

Mean global per capita factor VIII usage	**2.20 IU**	*68 countries reporting*
Median global per capita factor VIII usage	**1.02 IU**	*68 countries reporting*
Mean global per capita factor IX usage	**0.36 IU**	*61 countries reporting*
Median global per capita factor IX usage	**0.20 IU**	*61 countries reporting*
Total reported annual global consumption of factor VIII concentrates	**4,583,364,827 IU**	*68 countries reporting*
Total reported annual global consumption of factor IX concentrates	**641,739,140 IU**	*61 countries reporting*

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 chart below shows average per capita factor use for the countries that reported in both the 2010 and 2011 surveys.

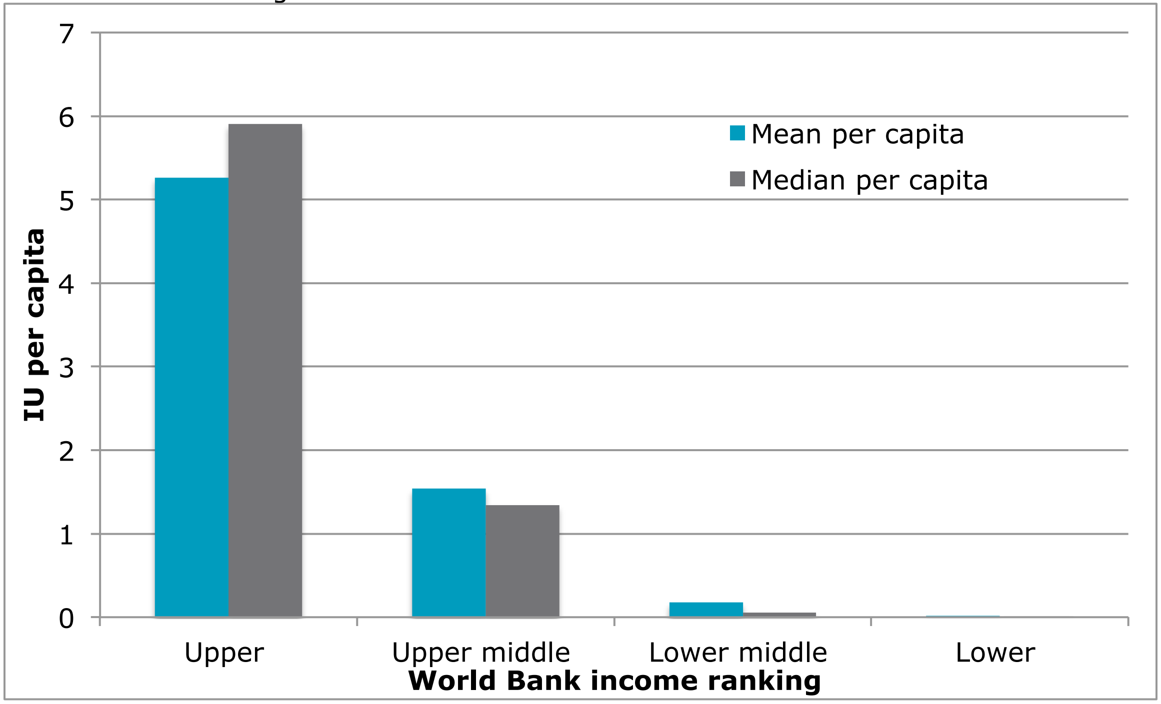
	2010	**2011**	
Mean global per capita factor VIII usage	**1.37 IU**	**1.60 IU**	*50 countries reporting*
Median global per capita factor VIII usage	**2.39 IU**	**2.50 IU**	*50 countries reporting*
Mean global per capita factor IX usage	**0.17 IU**	**0.22 IU**	*45 countries reporting*
Median global per capita factor IX usage	**0.38 IU**	**0.39 IU**	*45 countries reporting*

A. Identified patients – all disorders

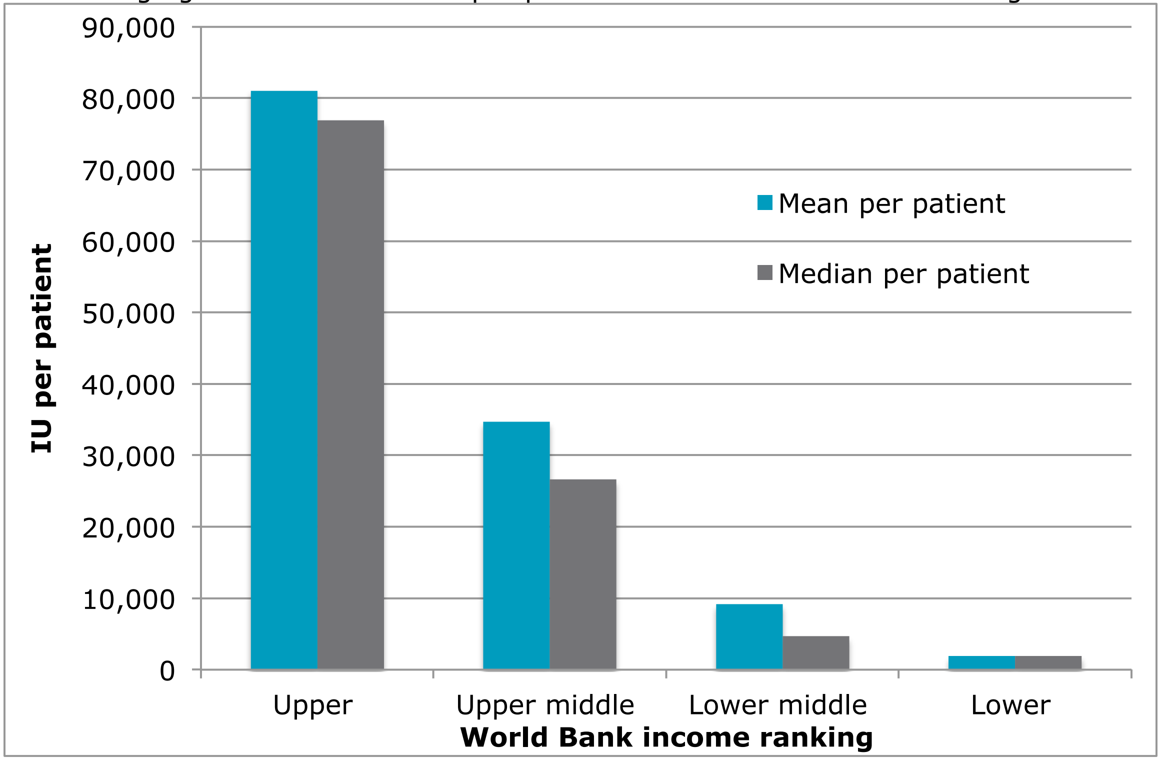


This graph showing the increase over time in patients identified contains data from the history of the Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. Collection of data for other bleeding disorders (rare factor deficiencies, and inherited platelet disorders) began in 2004. 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. Categories are based on the rankings for 2010.

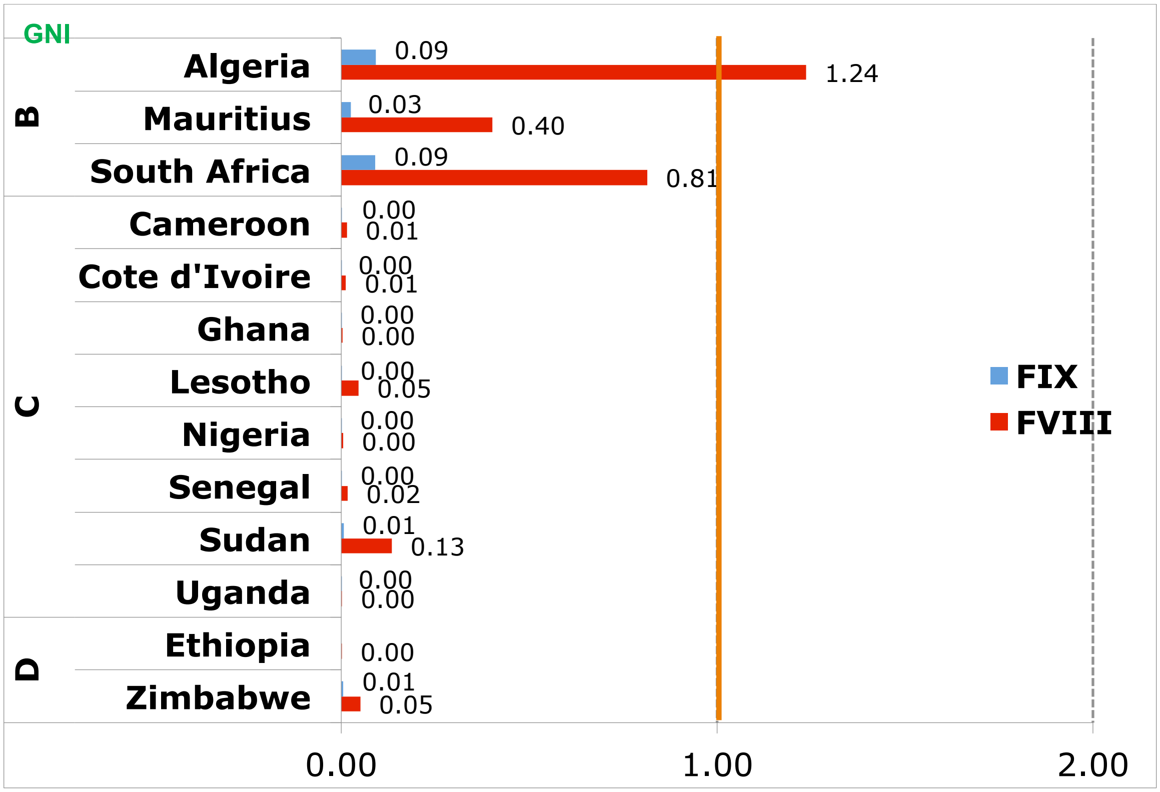


B2. Average global factor VIII use per patient based on World Bank rankings.



(Gross national income per capita in US dollars: lower income, $0-$995; lower middle income, $996 - $3,945; upper middle income, $3,946 - $12,195; and high income, $12,196 or more.)

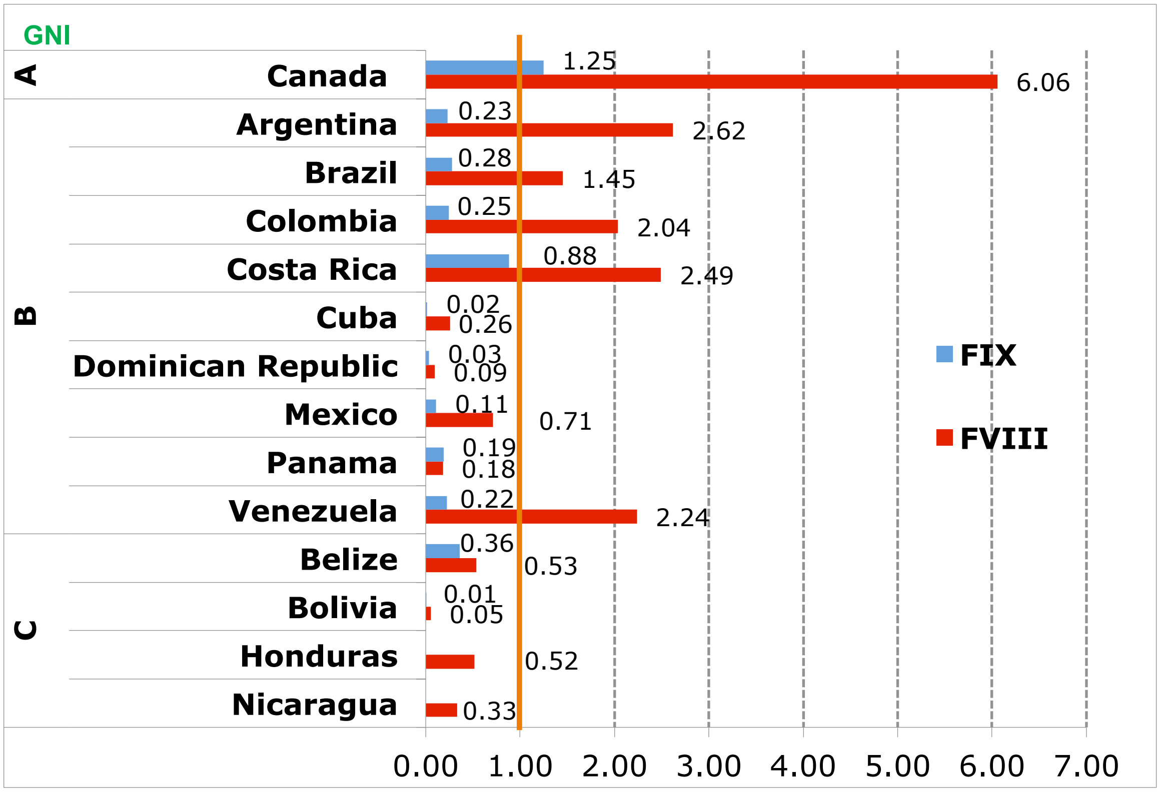
C1. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **Africa**



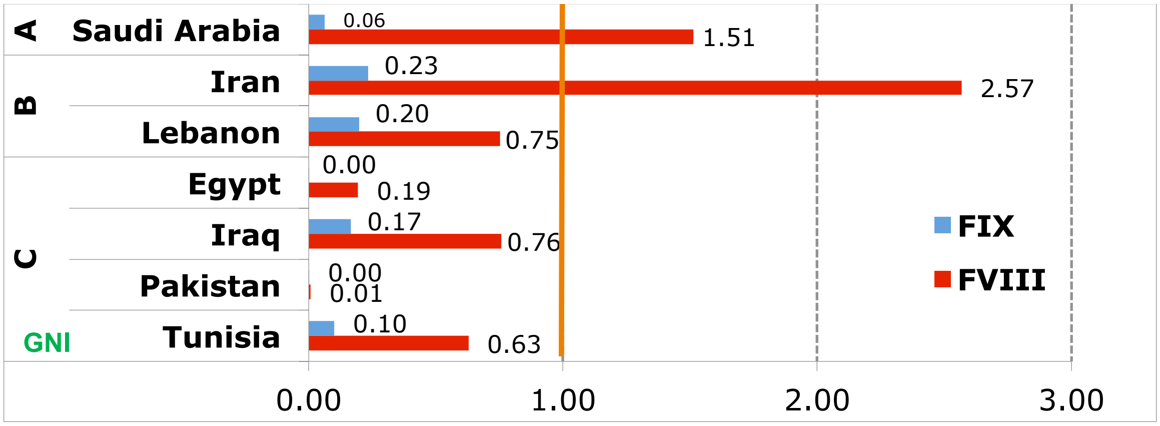
Economic category based on World Bank rankings. Categories are based on the rankings for 2010. (GNI in US dollars: D lower income, $0-$995; C lower middle income, $996 - $3,945; B upper middle income, $3,946 - $12,195; and A high income, $12,196 or more.)

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 number was reported. Only countries that completed the 2011 questionnaire are included in these charts.

C2. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **Americas**



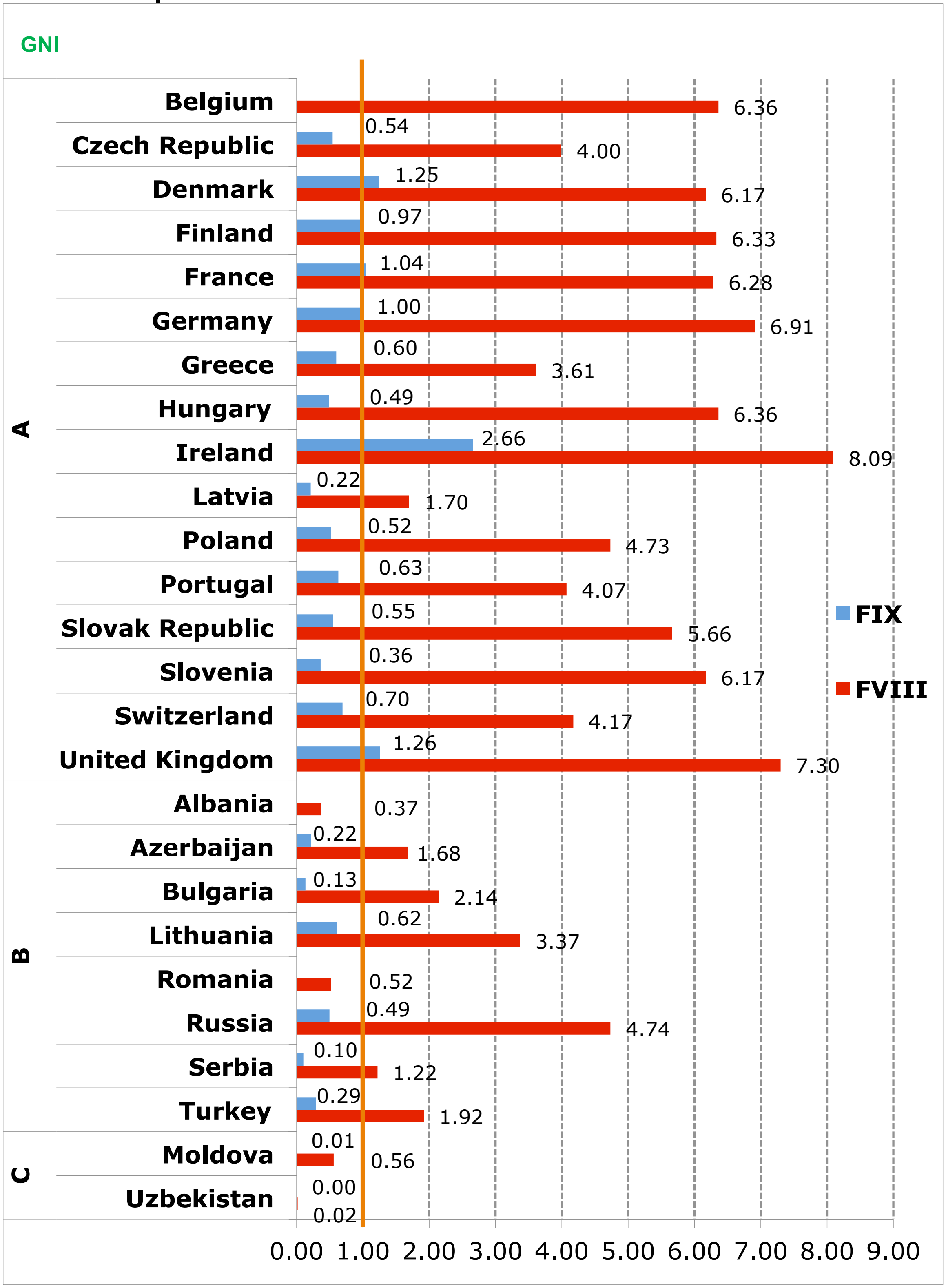
C3. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **Eastern Mediterranean**



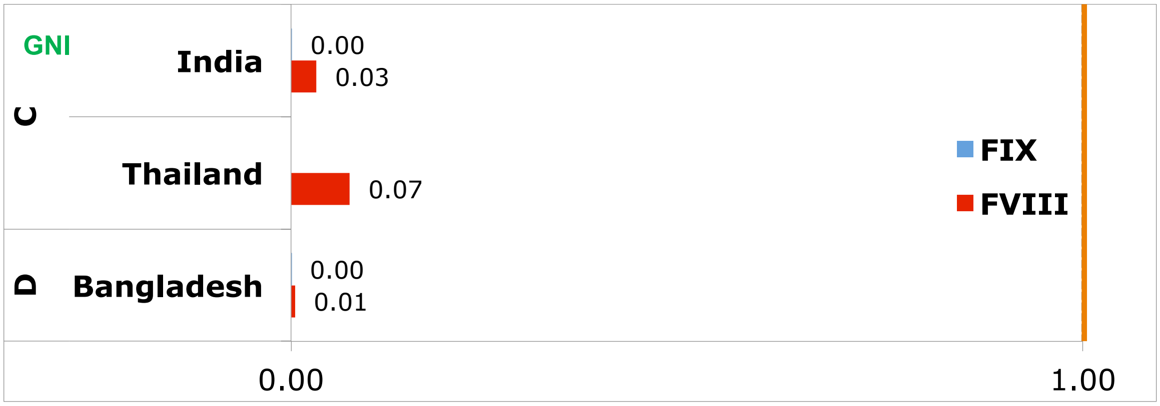
Economic category based on World Bank rankings. Categories are based on the rankings for 2010. (GNI in US dollars: D lower income, $0-$995; C lower middle income, $996 - $3,945; B upper middle income, $3,946 - $12,195; and A high income, $12,196 or more.)

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 number was reported. Only countries that completed the 2011 questionnaire are included in these charts.

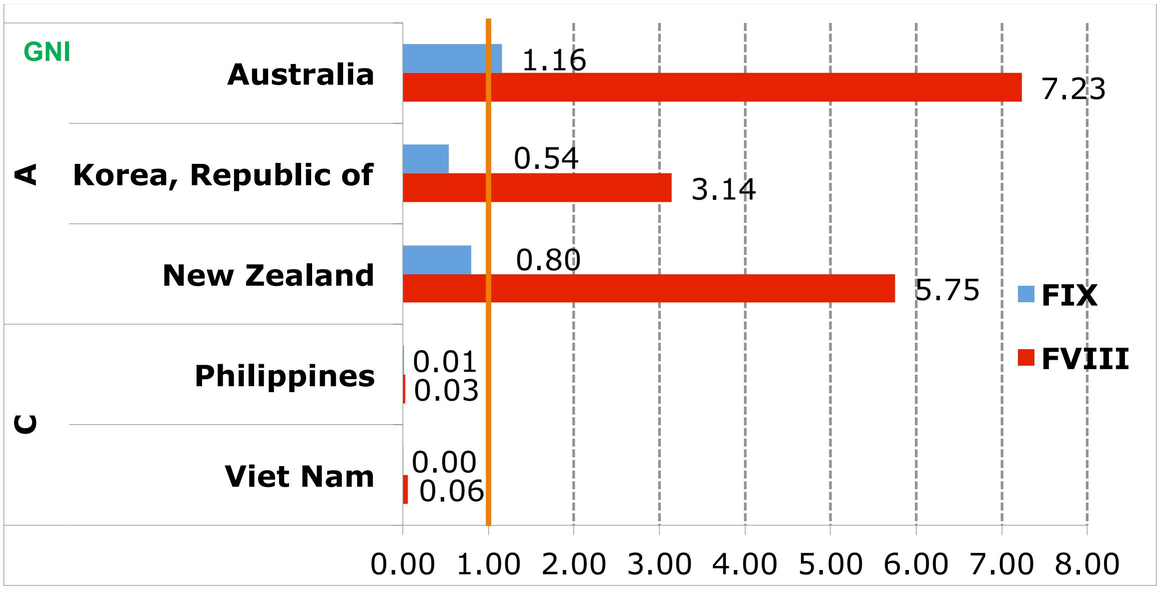
C4. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **Europe**



C5. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **South-East Asia**



C6. Mean per capita factor use in 2011 – regional and GNI comparisons of IU/total population: **Western Pacific**



Economic category based on World Bank rankings. Categories are based on the rankings for 2010. (GNI in US dollars: D lower income, $0-$995; C lower middle income, $996 - $3,945; B upper middle income, $3,946 - $12,195; and A high income, $12,196 or more.)

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 number was reported. Only countries that completed the 2011 questionnaire are included in these charts.

Countries included in the 2011 WFH Global Survey Report

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 2011 survey report, 83 countries submitted data for 2011. The data used from other years is as follows. 2010: 13 countries, 2009: 6 countries, 2008: 2 countries, 2007: 4 countries. For countries that did not complete a 2011 survey form but are part of the WFH GAP program, WFH data on the total number of patients identified and factor use in 2011 was used. All other data are from the year indicated. 2007 to 2010 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2011 only.

Albania	2011
Algeria	2011
Argentina	2011
Armenia	2009
Australia	2011
Austria	2011
Azerbaijan	2011
Bahrain	2011
Bangladesh	2011
Belarus	2010
Belgium	2011
Belize	2011
Bolivia	2011
Brazil	2011
Bulgaria	2011
Cambodia	2011
Cameroon	2011
Canada	2011
Chile	2009
China	2011
Colombia	2011
Costa Rica	2011
Cote d'Ivoire	2011
Croatia	2007
Cuba	2011
Czech Republic	2011
Denmark	2011
Dominican Republic	2011
Ecuador	2011
Egypt	2011
Eritrea	2011
Ethiopia	2011
Finland	2011
France	2011
Georgia	2010
Germany	2011
Ghana	2011
Greece	2011
Guatemala	2010
Honduras	2011
Hungary	2011
Iceland	2007
India	2011
Indonesia	2010
Iran	2011
Iraq	2011
Ireland	2011
Israel	2010
Italy	2007
Japan	2011
Jordan	2011
Kazakhstan	2008
Kenya	2011
Korea, Republic of	2011
Kuwait	2011
Kyrgyzstan	2010
Latvia	2011
Lebanon	2011
Lesotho	2011
Lithuania	2011
Macedonia	2011
Malaysia	2010
Mauritius	2011
Mexico	2011
Moldova	2011
Mongolia	2010
Nepal	2011
Netherlands	2011
New Zealand	2011
Nicaragua	2011
Nigeria	2011
Norway	2008
Oman	2010
Pakistan	2011
Palestine	2010
Panama	2011
Paraguay	2009
Peru	2010
Philippines	2011
Poland	2011
Portugal	2011
Romania	2011
Russia	2011
Saudi Arabia	2011
Senegal	2011
Serbia	2011
Slovak Republic	2011
Slovenia	2011
South Africa	2011
Spain	2011
Sri Lanka	2010
Sudan	2011
Sweden	2009
Switzerland	2011
Syria	2009
Tanzania	2011
Thailand	2011
Tunisia	2011
Turkey	2011
Uganda	2011
Ukraine	2007
United Kingdom	2011
United States	2010
Uruguay	2009
Uzbekistan	2011
Venezuela	2011
Viet Nam	2011
Zimbabwe	2011

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 2011. For countries that did not report population statistics for 2011 but did report during the years 2007-2010, we used the most recent number of patients reported. 2007 to 2010 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2011 only.)

Country	**Population**	**People with hemophilia**	**People with von Willebrand disease**	**People with other bleeding disorders**
Albania	3,215,988	292	2	Not known
Algeria	35,980,193	1,935	85	119
Argentina	40,764,561	2,133	355	Not known
Armenia	3,100,236	208	10	10
Australia	22,620,600	2,628	1,966	666
Austria	8,419,000	645	37	35
Azerbaijan	9,168,000	1,163	200	80
Bahrain	1,323,535	38	40	13
Bangladesh	150,493,658	543	0	8
Belarus	9,473,000	745	171	45
Belgium	11,008,000	1,159	1,467	302
Belize	356,600	15	Not known	Not known
Bolivia	10,088,108	96	2	1
Brazil	196,655,014	10,558	4,937	1,855
Bulgaria	7,476,000	618	90	33
Cambodia	14,305,183	75	1	2
Cameroon	20,030,362	102	1	0
Canada	34,482,779	3,380	3,563	1,460
Chile	17,269,525	1,252		
China	1,344,130,000	10,182	52	46
Colombia	46,927,125	1,963	229	161
Costa Rica	4,726,575	200	66	28
Cote d'Ivoire	20,152,894	59	2	3
Croatia	4,407,000	477	282	139
Cuba	11,253,665	407	139	2,224
Czech Republic	10,546,000	990	400	Not known
Denmark	5,574,000	477	341	87
Dominican Republic	10,056,181	257	71	123
Ecuador	14,666,055	479	89	8

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Egypt	82,536,770	4,829	474	1,037
Eritrea	5,415,280	60	Not known	Not known
Ethiopia	84,734,262	56	20	0
Finland	5,387,000	433	3,009	42
France	65,436,552	5,735	1,330	375
Georgia	4,486,000	256	22	10
Germany	81,726,000	4,654	4,447	
Ghana	24965816	51	1	Not known
Greece	11,304,000	899	792	185
Guatemala	14,757,316	114	18	2
Honduras	7,754,687	203	3	
Hungary	9,971,000			
Iceland	319,000	64	96	
India	1,241,491,960	11,580	1,685	1,353
Indonesia	242,325,638	1,388	Not known	Not known
Iran	74,798,599	5,318	1,029	2,182
Iraq	32,961,959	944	215	216
Ireland	4,487,000	739	817	1,619
Israel	7,765,700	540	4	1
Italy	60,770,000	3,270	1,650	700
Japan	127,817,277	5,446	984	410
Jordan	6,181,000	332	215	231
Kazakhstan	16,558,459	1,360	460	108
Kenya	41,609,728	613	18	16
Korea, Republic of	49,779,000	1,908	93	102
Kuwait	2,818,042	Not known	Not known	Not known
Kyrgyzstan	5,507,000	320	10	
Latvia	2,220,000	143	102	Not known
Lebanon	4,259,405	163	107	65
Lesotho	2,193,843	22	Not known	Not known
Lithuania	3,203,000	166	302	15
Macedonia	2,063,893	315	Not known	Not known
Malaysia	28,859,154	1,188	464	346
Mauritius	1,286,051	44	1	7
Mexico	114,793,341	4,632	214	25
Moldova	3,559,000	234	6	3

Country	**Population**	**People with hemophilia**	**People with von Willebrand disease**	**People with other bleeding disorders**
Mongolia	2,800,114	75	4	Not known
Nepal	30,485,798	392	1	13
Netherlands	16,696,000	1,397	2,500	65
New Zealand	4,405,200	416	186	23
Nicaragua	5,869,859	247	54	7
Nigeria	162,470,737	132	6	
Norway	4,952,000	397	858	37
Oman	2,846,145	97	281	271
Pakistan	176,745,364	1,589	391	314
Palestine	4,019,433	135	10	63
Panama	3,571,185	265	408	29
Paraguay	6,277,000	448	1	1
Peru	29,399,817	743	144	17
Philippines	94,852,030	1,131	29	
Poland	38,216,000	2,734	1,206	464
Portugal	10,637,000	641	48	23
Romania	21,390,000	1,610	348	9
Russia	141,930,000	5,421	1,254	954
Saudi Arabia	28,082,541	326	75	36
Senegal	12,767,556	116	4	6
Serbia	7,261,000	469	210	17
Slovak Republic	5,440,000	572	532	
Slovenia	2,052,000	204	162	96
South Africa	50,586,757	1,996	591	214
Spain	46,235,000	1,953	710	211
Sri Lanka	20,869,000	664	Not known	Not known
Sudan	34,318,385	663	171	170
Sweden	9,453,000	1,020	1,538	
Switzerland	7,907,000	701	136	70
Syria	20,820,311	465	30	16
Tanzania	46,218,486	56	1	
Thailand	69,518,555	1,260	69	53
Tunisia	10,673,800	363	82	
Turkey	73,639,596	4,651	728	1,086
Uganda	34,509,205	15	Not known	Not known
Ukraine	45,706,100	2,600		

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
United Kingdom	62,641,000	6,575	9,301	7,583
United States	311,591,917	17,485	13,239	1,772
Uruguay	3,368,595	236	316	11
Uzbekistan	29,341,200	1,291	91	25
Venezuela	29,278,000	2,144	752	830
Viet Nam	87,840,000	2,000	76	207
Zimbabwe	12,754,378	320	Not known	Not known
Total	6,365,209,633	167,110	69,729	31,191

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 2011.)

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Glanzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
Albania	254	38		2					1		1					
Algeria	1,540	356		85	17	2	10	15	49	4	3	5		4		
Argentina	1,873	260	158	355												21
Armenia	184	18		10	5				2	2	1			1		
Australia	2,109	517		1,966			13		53	12	151	17	196	10	1	180
Austria	546	99	0	37	0	0	5	1	12	3	7	3	0	0	0	0
Azerbaijan	1,065	98		200			5	11	12	10	3	2	37		6	
Bahrain	34	4	0	40	0	2	0	0	2	10	7	0				
Bangladesh	471	72	6	0	1							1				
Belarus	452	94		171					14	1	26	4				
Belgium	941	212	3	1,467	1	1	20		68	3	90	2	62	19		4
Belize	10	5														
Bolivia	84	10							1				131			
Brazil	8,839	1,719		4,937	45	11	91	14	382	64	112	39	777	154	33	
Bulgaria	560	68		90		1			5	3	2	3	8	11		
Cambodia	64	11		1								1		1		2
Cameroon	99	3	0	1	0	0	0		0	0	0	0	0	0	0	0
Canada	2,722	658		3,563	78	11	50	4	246	21	322	51	80	53	28	553
Chile	1,068	184														
China	8,921	1,261		52	2	0	3	1	8	2	15	2	169	0	0	0
Colombia	1,488	308	164	229	15	9	9	2	17	1	11	7	37	5	5	25
Costa Rica	169	31		66	1		1		12	5	5	4				
Cote d'Ivoire	54	5		2						2	1					
Croatia	385	92	0	282	6	0	12	3	48	3	19	7	3			17
Cuba	337	70	0	139	2	1	1	0	1	0	12	7	8	2	0	2,190
Czech Republic	858	132		400												
Denmark	384	91		341	1	1	2		4	7	5	11		8	7	43
Dominican Republic	220	37		68					7	22		3		3		1
Ecuador	396	83		88	1		1		1	1	3	1				
Egypt	3,861	967		474	126	8	154	6	86	99	91	29	21	410	8	
Eritrea	54	6														
Ethiopia	48	8	61	20												
Finland	337	96		3,009	3	1	5		10	7	2	13				
France	4,704	1,031	0	1,330	38	1	38	8	118	18	129	25	0			

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Glanzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
Georgia	218	38	10	22					2			1				6
Germany	3,957	697		4,447												
Ghana	50	1		1												
Greece	752	147		792	16	0	13	0	57	6	61	9		13	10	
Guatemala	108	6		18					1					1		
Honduras	183	19		3					3		1	1				
Iceland	63	2	0	96										0	12	
India	11,586	1,687	879	354	8	4	20	1	22	24	27	55	51			
Indonesia	334	48	1,006													
Iran	4,386	932	0	1,029	111	21	129	173	375	141	121	183	157	427	75	263
Iraq	706	238		215	34	1	1	1	53	11	8	20				87
Ireland	539	200	0	817	0	0	100	0	82	85	142	6	416	27	3	243
Israel	458	92		21												
Italy	2,697	573	21	1,650	49	14	73	23	308	54	156	21	45			115
Japan	4,475	971		984	59	7	29	9	64	19	28	57				
Jordan	253	79		215		4	12		43	22	38	11		100	1	
Kazakhstan	1,036	324		460												
Kenya	412	57		18									16			
Korea, Republic of	1,553	355	0	93	6	0	4	8	31	2	14	5	32			
Kyrgyzstan	209	17	84	10										5	2	
Latvia	118	25		102					2							
Lebanon	130	33	0	107	34	0	9	0	4	5	5	2	0	1	0	5
Lithuania	146	20		302					11	2		2				
Macedonia	210	105														
Malaysia	1,008	180		464	4	2	18	1	43	14	40	13		42	0	35
Mauritius	40	4		1					3	1	1					2
Mexico	3,747	561	349	214			2	1	13	4	2	2		1		
Moldova				6					1		4					
Mongolia	62	13		4												
Nepal	345	47		1		1			1	9		2				
Netherlands	1,195	202		2,500												
New Zealand	341	76		186	0	0	0	0	8	1	2	1	7	0	0	3
Nicaragua	219	28		54	4		2							3		
Norway	301	96	0		3		2	0	23	0	0					
Oman	90	7		281	5	1	6	5	48	3	17	1	8	24	2	151
Pakistan	1,376	313	0	393	16	1	23	9	32	16	3	36	172	92	10	2
Palestine	107	28		10	12		2			11				36	2	
Panama	237	28	0	408					8	11	0	0		3	1	7
Paraguay	434	14		1					1							

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Glanzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
Peru	577	103	63	144	0	0	1	0	8	0	5	1	0	1	0	0
Philippines	945	145	41	29												
Poland	2,348	386		1,206		0	20	3	198	17	34	10		18	2	7
Portugal	531	110		48	2		3		2	1	7	1	43	1		6
Romania	1,415	195	15	348		1		2	5		1					
Russia	4,720	701		1,254									954			
Saudi Arabia	260	66	0	75	0	2	3	1	6	1	9	13	0	66	2	0
Senegal	108	8		4			1		3							2
Serbia	400	69		210	1			1	5		5	4	1		1	
Slovak Republic	498	74		532	73	0	58	2	580	24	48	3		10	15	16
Slovenia	183	21		162			9	2	11		16	1		3		
South Africa	1,685	311		591	7	0	42	5	18	9	30	7		16	24	50
Spain	1,679	277		709	15	3	13	3	25	9	24	17	152	15		
Sri Lanka	498	137	29													
Sudan	562	101		171	17	1	26		19	11		28				66
Switzerland	585	116	0	136	11	0	0	4	29	4	8	14				
Syria	252	48		30	5		2	3	2	1				3		
Tanzania	27	8	22													
Thailand	294	51		69	1	0	2	1	14	1	0	0	0			
Tunisia	293	70	0	81	24	1	14	6	31	6	12	15	6	62	8	5
Turkey	3,926	725		728	15		25		401	103	16	80	389	16		
Uganda	7	6	3													
United Kingdom	5,424	1,151		9,301	175	11	141	23	730	188	2,030	60		110	62	1,376
United States	13,276	4,209		13,239	123	48	163		730	89	504	115				
Uruguay	185	30	21	316	1		2		3	1	2		2	1	1	
Uzbekistan	1,194	97		92	1	2			7		8		25	8		15
Venezuela	1,695	449		752	19	65	29	27	117	103	308	16		14	4	116
Viet Nam	1,272	234		76	3	5	1	6	15	8	4	4	21	84		49
Zimbabwe	303	16	1													
Total	134,354	26,821	2,936	66,007	1,196	244	1,420	385	5,357	1,317	4,759	1,054	4,026	1,884	325	5,663

Gender distributions

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	91	119,706	114,484	96	2,663	2	2,559	2
Hemophilia B	91	24,283	22,794	94	877	4	612	3
Hemophilia type unknown	91	1,825	1,650	90	114	6	61	3
Von Willebrand Disorder	67	56,874	22,596	40	33,494	59	784	1
Factor I Deficiency	62	1,109	477	43	562	51	70	6
Factor II Deficiency	62	230	119	52	107	47	4	2
Factor V Deficiency	62	1,315	558	42	640	49	117	9
Factor V+VIII Deficiency	62	352	200	57	151	43	1	0
Factor VII Deficiency	62	4,914	2,474	50	2,385	49	55	1
Factor X Deficiency	62	1,246	628	50	557	45	61	5
Factor XI Deficiency	62	4,567	2,124	47	2,357	52	86	2
Factor XIII Deficiency	62	1,007	598	59	390	39	19	2
Bleeding Disorder: Type Unknown	62	2,819	1,532	54	1,283	46	4	0
Platelet disorders: Glanzmanns thrombasthenia	62	1,814	748	41	779	43	287	16
Platelet disorders: Bernard Soulier Syndrome	62	309	148	48	157	51	4	1
Platelet disorders: other or unknown	62	5,491	2,111	38	3,380	62	0	0

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

Country	Hemophilia A w/ clinically identified inhibitors	Hemophilia B w/ clinically identified inhibitors
Algeria	35	0
Argentina	278	10
Australia	185	7
Austria	26	2
Azerbaijan	12	
Belize	0	0
Bolivia	1	
Brazil	747	32
Bulgaria	18	1
Cameroon	3	0
Canada	80	5
China	77	3
Colombia	66	5
Costa Rica	19	0
Cote d'Ivoire	1	0
Cuba	61	0
Czech Republic	12	2
Denmark	11	1
Dominican Republic	3	0
Egypt	25	1
France	105	5
Germany	68	12
Greece	22	3
Honduras	3	
Iran	239	7
Iraq	20	1
Ireland	8	2
Japan	81	18
Jordan	18	1
Latvia	2	2
Lebanon	6	
Lithuania	7	0
Macedonia	2	1
Mauritius	0	0
Mexico	192	10
New Zealand	30	0
Nicaragua	1	
Pakistan	36	6
Panama	13	0
Philippines	10	2
Poland	172	3
Romania	102	3
Saudi Arabia	23	0
Serbia	19	0
Slovak Republic	6	1
Slovenia	2	
Spain	76	6
Sudan	10	1
Switzerland	7	1
Turkey	116	14
United Kingdom	187	12
Uzbekistan	32	
Venezuela	85	3
Viet Nam	24	
Zimbabwe	3	
Totals	**3,387**	**183**

Age distribution: hemophilia A (62 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Argentina	86	271	213	848	390	65
Australia	96	263	153	854	744	
Austria	10	72	50	255	159	0
Azerbaijan	21	105	96	633	201	
Bahrain	3	6	5	20		0
Bangladesh	20	141	112	173	25	0
Belgium	34	119	82	331	370	5
Belize	1	5	3	1		
Bolivia	17	23	13	14	6	11
Brazil	542	1,647	1,116	4,214	1,271	49
Cambodia	19	31	7	7		
Cameroon	40	14	30	13	2	0
Canada	143	387	236	1,141	815	
China	473	1,975	1,003	4,275	486	709
Colombia	28	140	146	482	141	551
Costa Rica	7	44	17	78	23	
Cote d'Ivoire	4	14	19	13	4	
Cuba	13	43	44	191	46	
Czech Republic	34	98	61	222	174	269
Egypt	1,360	186	65	301	33	1,916
Eritrea	1	17	8	20	3	5
Ethiopia	9	18	12	9	0	
France	260	768	465	2,020	1,191	0
Ghana	10	18	17	5		
Greece	17	82	27	345	281	
Honduras	18	46	26	65	3	25
India	467	2,000	1,194	3,614	602	3,709
Iran	254	594	389	2,582	567	
Iraq	143	252	136	155	20	
Ireland	30	95	41	222	151	0
Kenya	116	137	66	57	36	
Korea, Republic of	74	233	181	836	229	
Latvia	6	14	10	57	29	2
Lebanon	10	25	11	65	17	2
Mauritius	2	5	6	16	8	
Mexico	142	659	466	1,479	300	701
Moldova	5	18	21	129	33	
Nepal	41	111	55	130	20	

Country	0-4	5-13	14-18	19-44	45+	Age not known
Netherlands	16	226	117	360	434	
New Zealand	20	64	37	134	70	16
Nigeria	12	52	41	24	1	
Pakistan	247	505	363	222	28	44
Panama	8	29	51	122	27	
Philippines	30	208	175	375	60	97
Poland	45	175	136	1,237	755	0
Portugal	11	64	23	230	158	45
Romania	3	88	95	715	445	69
Saudi Arabia	56	92	51	59		
Senegal	7	33	15	44	2	0
Serbia	22	47	41	169	121	
Slovak Republic	21	44	29	226	178	0
Slovenia	5	17	5	90	66	
South Africa	86	291	180	746	337	45
Spain	35	153	92	782	471	146
Sudan	55	181	109	200	17	
Switzerland	15	61	44	240	225	0
Tanzania	2	5	5	3	1	11
Turkey	190	904	572	1,734	498	28
Uganda	3	4		3		
United Kingdom	341	716	467	2,092	1,805	3
Uzbekistan	28	163	295	501	44	50
Viet Nam	103	285	115	281	79	399
Total	5,917	15,083	9,660	36,461	14,202	8,972

Age distribution: hemophilia B (62 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Argentina	10	45	40	107	51	7
Australia	13	71	27	236	170	
Austria	4	15	11	38	31	0
Azerbaijan	5	18	17	36	22	
Bahrain	2	1	0	1	0	0
Bangladesh	4	25	24	17	2	0
Belgium	10	22	18	81	79	2
Belize		2	1	2		
Bolivia	2	2	4	2		
Brazil	93	357	226	768	271	4
Cambodia	5	2	2	2		
Cameroon	3	0	0	0	0	0
Canada	30	65	72	280	211	
China	62	238	136	623	82	120
Colombia	7	39	24	101	28	109
Costa Rica	2	5	5	16	3	
Cote d'Ivoire		1	2	2		
Cuba	4	10	9	34	13	
Czech Republic	7	11	8	34	24	48
Egypt	318	29	14	55	7	544
Eritrea			2	3		1
Ethiopia	2	2	1	3	0	
France	61	166	107	439	258	0
Ghana		1				
Greece	2	13	1	73	58	
Honduras		6	6	7		
India	61	306	205	579	113	423
Iran	31	121	74	573	133	
Iraq	36	77	53	53	19	
Ireland	9	11	16	97	67	0
Kenya	3	15	29	28	2	
Korea, Republic of	20	72	41	174	48	
Latvia	1	3	1	16	3	1
Lebanon	0	8	5	15	5	0
Mauritius		2		2		
Mexico	21	90	82	230	53	85
Moldova	1	1	2	8	5	
Nepal	5	18	4	18	3	

Country	0-4	5-13	14-18	19-44	45+	Age not known
Netherlands	1	39	23	65	67	
New Zealand	4	7	5	33	26	2
Nigeria		1		1		
Pakistan	34	80	37	48	51	53
Panama	2	7	5	13	1	
Philippines	2	32	27	57	13	14
Poland	0	10	24	189	101	0
Portugal	1	13	5	48	33	10
Romania	2	11	13	80	80	9
Saudi Arabia	4	26	4	28		
Senegal	5	2	1	0	0	0
Serbia	7	12	5	32	13	
Slovak Republic	7	8	6	31	22	0
Slovenia		1	1	11	8	
South Africa	19	58	28	132	70	4
Spain	7	26	13	126	87	18
Sudan	16	39	18	27	1	
Switzerland	0	8	14	53	41	0
Tanzania		5		1		2
Turkey	41	179	108	303	87	7
Uganda	3	2				
United Kingdom	81	131	86	498	355	0
Uzbekistan	3	18	13	56	4	16
Viet Nam	13	17	26	67	16	95
Total	1,086	2,602	1,731	6,652	2,837	1,574

Age distribution: VWD (56 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Argentina	0	8	16	179	99	53
Australia	24	204	154	813	711	
Austria	0	6	4	18	8	0
Azerbaijan	9	21	35	95	40	
Bahrain	0	5	31	4		0
Bangladesh	0	0	0	0	0	0
Belgium	30	261	120	606	439	11
Bolivia		2				
Brazil	63	683	598	2,428	1,138	27
Cambodia		1				
Cameroon	1	0	0	0	0	0
Canada	49	408	349	1,700	1,057	
China	1	14	8	21		8
Colombia	3	4	45	82	10	85
Cote d'Ivoire				2		
Cuba	0	19	22	60	38	
Egypt	195	8	6	25	3	237
Ethiopia			2	17	1	
France	36	234	108	527	425	0
Ghana						1
Greece	3	118	53	381	237	
Honduras			1	2		
India	11	59	30	121	11	122
Iran	56	135	121	612	105	
Iraq	43	60	83	25	4	
Ireland	41	56	62	443	215	0
Kenya	3	10	2	3		
Korea, Republic of	0	11	21	50	11	
Latvia			2	66	30	4
Lebanon	4	27	17	46	10	3
Mauritius				1		
Mexico	6	31	26	69	11	71
Moldova			1	5		
Nepal		1				
Netherlands	150	210	300	650	675	500
New Zealand	3	24	24	64	43	28
Nigeria			2	4		
Pakistan	64	126	116	52	11	42

Country	0-4	5-13	14-18	19-44	45+	Age not known
Panama	10	216	33	110	39	
Philippines	0	4	2	10	0	13
Poland	45	118	140	594	309	0
Portugal	0	2	4	16	23	3
Romania	0	9	22	232	62	23
Saudi Arabia	4	10	34	26		
Senegal	0	3	1	0	0	0
Serbia	6	20	8	124	52	
Slovak Republic	6	44	26	308	148	0
Slovenia	3	22	10	91	36	
South Africa	7	53	55	257	192	27
Spain	4	18	20	271	278	118
Sudan	33	69	29	36	4	
Switzerland	1	5	10	62	58	0
Turkey	39	219	137	277	50	6
United Kingdom	265	955	776	4,011	3,289	5
Uzbekistan	5	19	16	38	8	6
Viet Nam	17	13	16	25	5	
Total	1,476	4,711	3,759	15,915	9,958	1,475

HIV and HCV infection (People currently living with HIV or HCV)

Country	hemophilia HIV+	hemophilia HCV+	vWD HIV+	vWD HCV+
Algeria	2		No data	
Argentina	63	623	No data	
Austria	49	140	1	5
Bahrain	0	0	0	0
Bangladesh	No data	1	No data	
Bolivia	No data	2	No data	
Bulgaria	10	400	0	
Cameroon	0	0	0	0
Canada	205	860	5	64
China	32	211	No data	
Colombia	5	130	0	5
Cote d'Ivoire	0	1	0	0
Cuba	4	151	0	9
Czech Republic	5	132	No data	
Denmark	27	100	No data	
Dominican Republic	1	1	No data	
Ethiopia	4	3	No data	
Finland	0		No data	
France	455	1,709	14	146
Germany	410		4	
Greece	64	309	1	27
Honduras		3		
India	159			
Iran	150	3,000	0	20
Iraq	0	200	0	60
Ireland	36	141	0	11
Japan	750	1,252	7	
Jordan	2	46	No data	
Kenya	22		0	
Korea, Republic of	17		0	
Lebanon	0	13		2
Lesotho	0	0		
Lithuania	0			
Mauritius	0	8	0	1
Mexico	24	121	1	2
Nepal		5	0	0
Netherlands	No data		10	15
New Zealand	6		1	6
Nicaragua	1	68	0	5
Pakistan	4	307	0	76
Panama	18	19	0	1
Romania	1	943		
Saudi Arabia	31	88		
Senegal	0		0	
Serbia	9	124	2	12

Country	hemophilia HIV+	hemophilia HCV+	vWD HIV+	vWD HCV+
Slovak Republic	0	145	0	23
Slovenia	7	89	0	6
South Africa	67	222	1	3
Spain	470	1,014	28	130
Sudan	1	38	0	6
Thailand	10	60	0	1
United Kingdom	314		5	
Uzbekistan	5	321	No data	10
Venezuela	85	322	9	25
Viet Nam	1	198	0	9
Totals	**3,526**	**13,520**	**89**	**680**

Reported Use of Factor Concentrates in 2011: 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 2011 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
Albania	1,200,000				0.373	0.373		
Algeria	44,469,500	36,954,000	7,515,500	0	1.236	1.236	83%	17%
Argentina	106,860,000	81,780,000	25,080,000		2.621	2.621	77%	23%
Australia	163,565,260	21,642,000	141,923,260		7.231	7.231	13%	87%
Azerbaijan	15,400,000	13,200,000	2,200,000		1.680	1.680	86%	14%
Bangladesh	755,192	467,500	287,692	341,692	0.005	0.003	62%	38%
Belgium	70,000,000	5,000,000	65,000,000		6.359	6.359	7%	93%
Belize	190,628	47,657	142,971	190,628	0.535	0.000	25%	75%
Bolivia	542,663		85,776	542,663	0.054	0.000		
Brazil	285,850,400	285,850,400		0	1.454	1.454	100%	0%
Bulgaria	16,000,000	14,000,000	2,000,000	0	2.140	2.140	88%	13%
Cameroon	292,654	38,800	152,224	292,654	0.015	0.000		
Canada	208,873,815	28,931,166	179,942,649	0	6.057	6.057	14%	86%
Colombia	95,578,000	55,900,000	39,678,000	40,000	2.037	2.036	58%	42%
Costa Rica	11,780,925	11,780,925			2.492	2.492	100%	0%
Cote d'Ivoire	251,573	0	251,573	251,573	0.012	0.000	0%	100%
Cuba	2,933,736	2,678,500	255,236	255,236	0.261	0.238	91%	9%
Czech Republic	42,140,000	37,926,000	4,214,000	0	3.996	3.996	90%	10%
Denmark	34,400,000	1,250,000	33,150,000	0	6.172	6.172	4%	96%
Dominican Republic	944,400	954,800	0	818,400	0.094	0.013	100%	0%
Egypt	16,000,000	10,000,000	6,000,000	500,000	0.194	0.188	63%	38%
Ethiopia	94000		94,000	94000	0.001	0.000	0%	100%
Finland	34,106,000	9,608,500	24,497,500	0	6.331	6.331	28%	72%
France	411,213,960	69,964,710	341,249,250		6.284	6.284	17%	83%
Germany	564,726,660				6.910	6.910		
Ghana	72,950	0	72,950	72,950	0.003	0.000	0%	100%
Greece	40,789,750	2,659,000	38,130,750	0	3.608	3.608	7%	93%
Honduras	4,000,000	4,000,000		175,484	0.516	0.493	100%	0%
Hungary	63,400,000	38,000,000	25,400,000	0	6.358	6.358	60%	40%
India	39,700,000	38,700,000	1,000,000	1,800,000	0.032	0.030	98%	2%
Iran	192,000,000	192,000,000	0	0	2.567	2.567	100%	0%
Iraq	25,000,000	0	25,000,000	0	0.758	0.758	0%	100%
Ireland	36,315,000	0	36,315,000	0	8.093	8.093	0%	100%
Korea, Rep. of	156,448,500	74,335,500	82,113,000		3.143	3.143	48%	52%

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
Latvia	3,763,000	3,763,000		0	1.695	1.695	100%	0%
Lebanon	3,201,561	1,200,000	2,001,561	799,561	0.752	0.564	37%	63%
Lesotho	100,000	0	0	0	0.046	0.046		
Lithuania	10,801,500	7,477,000	3,324,500	0	3.372	3.372	69%	31%
Mauritius	516,500	95	0	0	0.402	0.402	0%	0%
Mexico	81,905,000	77,323,000	4,582,000	2,542,920	0.713	0.691	94%	6%
Moldova	2,001,828	817,328	1,184,500	1,489,828	0.562	0.144	41%	59%
New Zealand	25,351,250	3,675,500	21,675,750	0	5.755	5.755	14%	86%
Nicaragua	1,956,332		1,956,332	1,956,332	0.333	0.000	0%	100%
Nigeria	777,648	140,672	636,976	777,648	0.005	0.000	18%	82%
Pakistan	1,410,551	333,713	767,246	989,847	0.008	0.002		
Panama	647,584	189,000	458,584	458,584	0.181	0.053	29%	71%
Philippines	2,609,906	645,077	1,964,829	1,976,362	0.028	0.007	25%	75%
Poland	180,803,100	180,288,850	514,250	0	4.731	4.731	100%	0%
Portugal	43,300,250	19,465,000	23,835,250		4.071	4.071	45%	55%
Romania	11,099,345	8,099,347	2,999,998		0.519	0.519	73%	27%
Russia	672,164,500	587,243,750	84,920,750	0	4.736	4.736	87%	13%
Saudi Arabia	42,496,000	8,499,200.00	33,996,800	0	1.513	1.513	20%	80%
Senegal	217,450		217,450	217,450	0.017	0.000	0%	100%
Serbia	8,870,000	8,870,000			1.222	1.222	100%	0%
Slovak Republic	30,800,000	29,500,000	1,300,000	0	5.662	5.662	96%	4%
Slovenia	12,661,650	3,079,250	9,582,400		6.170	6.170	24%	76%
South Africa	41,146,550	39,610,300	1,536,250	0	0.813	0.813	96%	4%
Sudan	4,612,022	4,199,250	412,772	412,772	0.134	0.122	91%	9%
Switzerland	33,000,000	7,100,000	25,900,000	0	4.174	4.174	22%	78%
Thailand	5,150,000	5,150,000		139,520	0.074	0.072	100%	0%
Tunisia	6,702,000	4,477,000	2,225,000	142,960	0.628	0.614	67%	33%
Turkey	141,218,500	114,056,500	27,162,000		1.918	1.918	81%	19%
Uganda	73,413			73,413	0.002	0.000		
United Kingdom	457,059,548	55,897,942	401,161,606		7.296	7.296	12%	88%
Uzbekistan	448,750	448,750		198,750	0.015	0.009	100%	0%
Venezuela	65,500,000	27,725,000	37,775,000		2.237	2.237	42%	58%
Viet Nam	5,103,523	4,235,564		692,870	0.058	0.050		
Zimbabwe	643,240	22,000	621,240	643,240	0.050	0.000	3%	97%
Totals	4,583,364,827	2,202,501,546	1,773,764,375	18,887,337	1.203	1.198	51%	49%

Reported Use of Factor Concentrates in 2011: 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 2011 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	3,300,000	3,300,000	0	0	0.09172	0.09172	100%	0%
Argentina	9,300,000	8,220,000	1,080,000		0.22814	0.22814	88%	12%
Australia	26,189,500	3,277,500	22,912,000		1.15777	1.15777	13%	87%
Azerbaijan	2,000,000	2,000,000			0.21815	0.21815	100%	0%
Bangladesh	30,000	30,000	0	30,000	0.00020	0.00000	100%	0%
Belize	128,822	34,205	94,617	128,822	0.36125	0.00000	27%	73%
Bolivia	56,000			56,000	0.00555	0.00000		
Brazil	55,316,950	55,316,950			0.28129	0.28129	100%	0%
Bulgaria	1,000,000	1,000,000	0	0	0.13376	0.13376	100%	0%
Cameroon	12,593	10,563	2,030	2,030	0.00063	0.00053	84%	16%
Canada	42,975,510	7,474,134	35,501,376	0	1.24629	1.24629	17%	83%
Colombia	11,640,000	8,927,000	2,677,000	6,700	0.24804	0.24790	77%	23%
Costa Rica	4,171,500	4,171,500			0.88256	0.88256	100%	0%
Cote d'Ivoire	5,000	0	5,000	5,000	0.00025	0.00000	0%	100%
Cuba	193,000	193,000			0.01715	0.01715	100%	0%
Czech Republic	5,733,000	5,733,000	0	0	0.54362	0.54362	100%	0%
Denmark	6,950,000	0	6,950,000	0	1.24686	1.24686	0%	100%
Dominican Republic	350,000		0	350,000	0.03480	0.00000		
Egypt	9,000			9,000	0.00011	0.00000		
Finland	5,241,000	1,032,500	4,208,500	0	0.97290	0.97290	20%	80%
France	67,956,750	31,768,000	36,188,750		1.03851	1.03851	47%	53%
Germany	81,726,000.0				1.00000	1.00000		
Ghana	16,000	0	16,000	16,000	0.00064	0.00000	0%	100%
Greece	6,765,600	519,100	6,246,500	0	0.59851	0.59851	8%	92%
Hungary	4,900,000	4,900,000	0	0	0.49143	0.49143	100%	0%
India	1,100,000	0	0	0	0.00089	0.00089		
Iran	17,500,000	17,500,000	0	0	0.23396	0.23396	100%	0%
Iraq	5,500,000	0	5,500,000	0	0.16686	0.16686	0%	100%
Ireland	11,938,250	0	11,938,250	0	2.66063	2.66063	0%	100%
Korea, Republic of	26,647,250	3,148,250	23,499,000		0.53531	0.53531	12%	88%
Latvia	480,400	100		0	0.21640	0.21640		

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
Lebanon	845,800	845,800		71,200	0.19857	0.18186	100%	0%
Lesotho	3,000	0	0	0	0.00137	0.00137		
Lithuania	1,970,000	1,970,000	0	0	0.61505	0.61505	100%	0%
Mauritius	33,000		0	0	0.02566	0.02566		
Mexico	12,867,400	12,867,400		349,200	0.11209	0.10905	100%	0%
Moldova	39,000	39,000		39,000	0.01096	0.00000	100%	0%
New Zealand	3,515,500	1,581,000	1,934,500	0	0.79803	0.79803	45%	55%
Nigeria	35,000		35,000	35,000	0.00022	0.00000	0%	100%
Pakistan	342,990	203,000	0	342,990	0.00194	0.00000		
Panama	672,750	172,750	500,000	500,000	0.18838	0.04837	26%	74%
Philippines	1,326,183	276,000	1,050,183	1,176,183	0.01398	0.00158	21%	79%
Poland	19794000	19,637,000	157,000	0	0.51795	0.51795	99%	1%
Portugal	6,729,000	4,490,000	2,239,000		0.63260	0.63260	67%	33%
Russia	70,000,000	70,000,000	0	0	0.49320	0.49320	100%	0%
Saudi Arabia	1,745,500	1,745,500	0	0	0.06216	0.06216	100%	0%
Senegal	14,000		14,000	9,000	0.00110	0.00039	0%	100%
Serbia	735,000	735,000			0.10123	0.10123	100%	0%
Slovak Republic	3,000,000	0	3,000,000	0	0.55147	0.55147	0%	100%
Slovenia	739,500	739,500			0.36038	0.36038	100%	0%
South Africa	4,609,000	4,609,000	0	0	0.09111	0.09111	100%	0%
Sudan	210,700	179,700	31,000	31,000	0.00614	0.00524	85%	15%
Switzerland	5,500,000	4,800,000	700,000	0	0.69559	0.69559	87%	13%
Tunisia	1,069,500	1,069,500	0	39,000	0.10020	0.09654	100%	0%
Turkey	21,427,200	21,427,200			0.29097	0.29097	100%	0%
Uganda	14,502			14,502	0.00042	0.00000		
United Kingdom	78,779,490	9,150,670	69,628,820		1.25763	1.25763	12%	88%
Uzbekistan	39000	39000		39,000	0.00133	0.00000	100%	0%
Venezuela	6,500,000	6,500,000			0.22201	0.22201	100%	0%
Viet Nam	50,000	50,000	0		0.00057	0.00057	100%	0%
Zimbabwe	72,600		72,600	72,600	0.00569	0.00000	0%	100%
Totals	641,739,140	321,682,822	236,181,126	3,322,227	0.17950	0.17857	63%	37%

Sample Survey Questionnaire

A. National Hemophilia Organization

Organization name	
Address	
City	
State, Province, Region, Prefecture, County	
Postal/ZIP Code	
Country	
Phone	
Fax	
E-mail	
Website	

B. Identified patients

(Please DO NOT estimate or guess)	**Number**	**Not known**
1. Number of identified people with **hemophilia A** and **B** (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)		☐

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**.**

4. 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):

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

Age group	Number with hemophilia A	Number with hemophilia B	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	☐	☐	☐

6.Type of hereditary bleeding disorder

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					☐
Other hereditary bleeding disorders: type unknown					☐
Platelet disorders: Glanzmann's thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

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

Factor level below 5% ☐	Severe bleeding symptoms ☐	Other ☐ (please describe):	No data ☐

How are patients with von Willebrand Disease identified?

Laboratory diagnosis ☐	Severe bleeding symptoms ☐	Other ☐ (please describe):	No data ☐

8. Number of identified people with hemophilia by diagnosis of severity

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					☐

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
			☐

10. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors. (Patients who do not respond to normal treatment.)

Type of hemophilia	Number with current inhibitors	No Data
Hemophilia A		☐
Hemophilia B		☐

11. Products used to treat hemophilia: What percentage of patients is treated with the following products?

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
Recombinant concentrate	%
DDAVP (Desmopressin)	%

12. Products used to treat vWD: What percentage of patients is treated with the following products?

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
DDAVP (Desmopressin)	%

13. HIV and hepatitis C infection among living people with hemophilia

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

14. HIV and hepatitis C infection among living people with von Willebrand disease

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

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2011)

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

D. The Cost and Use of Factor Concentrates

18. Annual usage of factor concentrates	Factor VIII	Factor IX	Not known
How many international units (IU) of factor concentrates were used in your country in 2011?			☐
How many international units of **plasma-derived** concentrates were used in your country in 2011?			☐
How many international units of **recombinant** concentrates were used in your country in 2011?			☐
How many international units were **humanitarian aid**?			☐

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 2011
(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

(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

(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

(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

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