

December 2013

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World Federation of Hemophilia  
Report on the

**ANNUAL GLOBAL  
SURVEY 2012**



**WFH**

50

YEARS OF ADVANCING  
TREATMENT FOR ALL

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

*Report on the Annual Global Survey 2012* is published by the World Federation of Hemophilia.

All data are provisional.

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## Introduction to the Report on the WFH Global Survey 2012

Report on the Annual Global Survey 2012 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 2012 survey is the thirteenth WFH survey. This report uses data for the years 2009, 2010, 2011 and 2012. Not all of our members are able to report every year. A list of participating countries and the last year they provided can be found on page 10. The survey includes data on more than 274,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 109 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 2012 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 2012 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 2012. 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 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, 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.



## 2012 WFH Global Survey summary

### Demographics

Number of countries in this survey	109
Percentage of world population covered by countries in 2012 survey report	91%
Number of people identified with hemophilia	172,373
Number of people identified with von Willebrand disease	66,144
Number of people identified with other bleeding disorders	35,549
Total number of people with bleeding disorders identified	274,066
Number of people with hemophilia A	142,205
Number of people with hemophilia B	28,008
Number of hemophilia A patients with clinically identified inhibitors	5,675
Number of hemophilia B patients with clinically identified inhibitors	306

These numbers are for the total number identified, not newly identified in this survey. 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

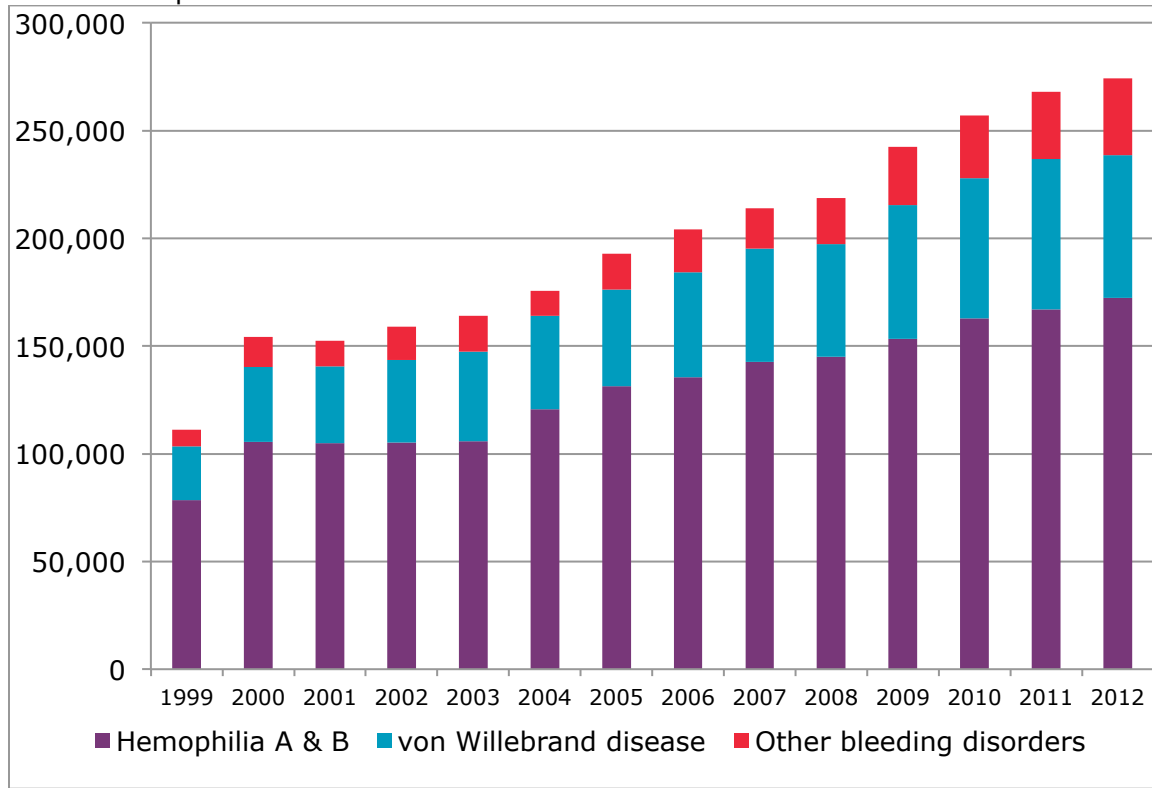
Mean global per capita factor VIII usage	2.60 IU	67 countries reporting
Median global per capita factor VIII usage	1.12 IU	67 countries reporting
Mean global per capita factor IX usage	0.39 IU	64 countries reporting
Median global per capita factor IX usage	0.18 IU	64 countries reporting
Total reported annual global consumption of factor VIII concentrates	6,733,122,643 IU	67 countries reporting
Total reported annual global consumption of factor IX concentrates	1,001,016,780 IU	64 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 2011 and 2012 surveys.

	2011	2012	
Mean global per capita factor VIII usage	2.46 IU	2.76 IU	50 countries reporting
Median global per capita factor VIII usage	1.23 IU	1.61 IU	50 countries reporting
Mean global per capita factor IX usage	0.37 IU	0.38 IU	47 countries reporting
Median global per capita factor IX usage	0.20 IU	0.19 IU	47 countries reporting

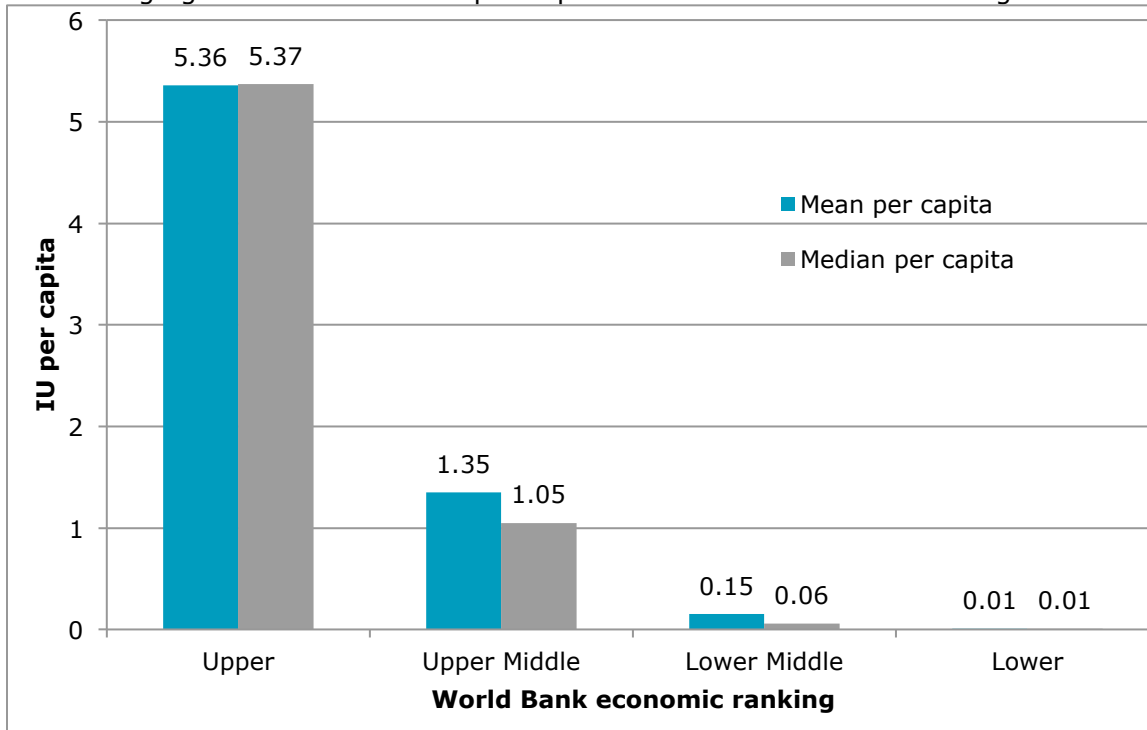
A. Identified patients – all disorders



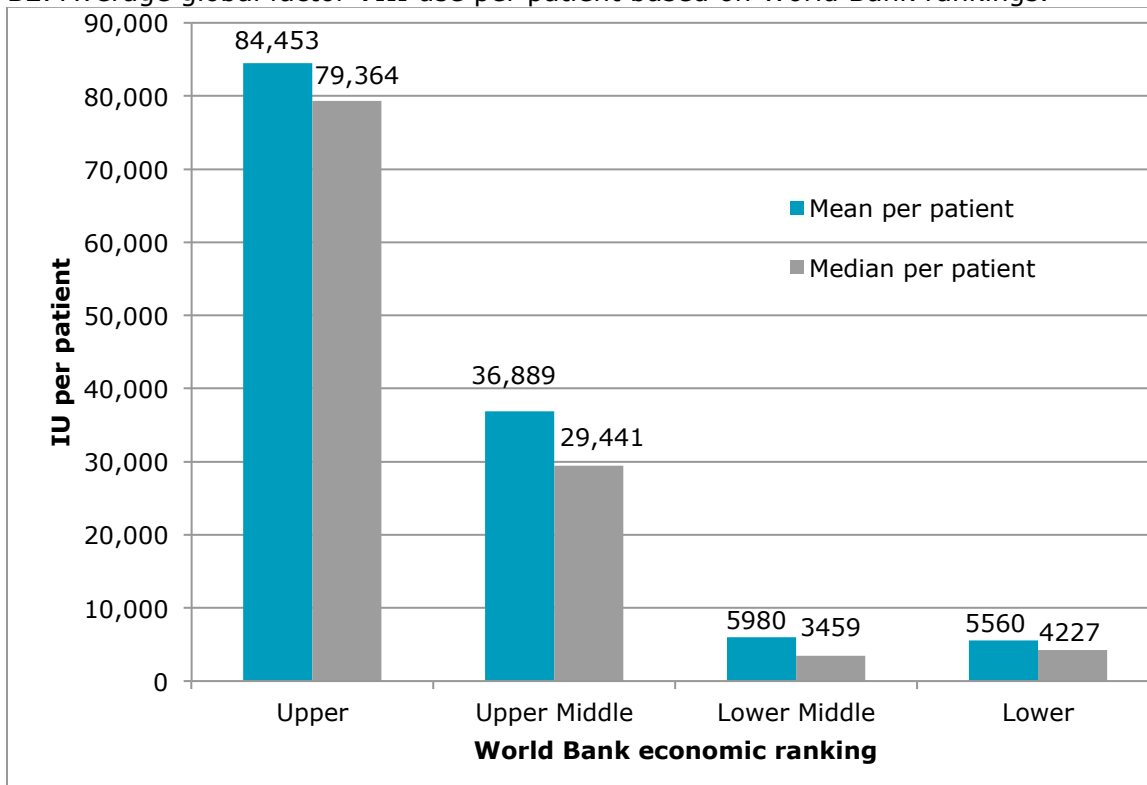
This graph showing the increase over time in patients identified contains data from the history of the Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were 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.

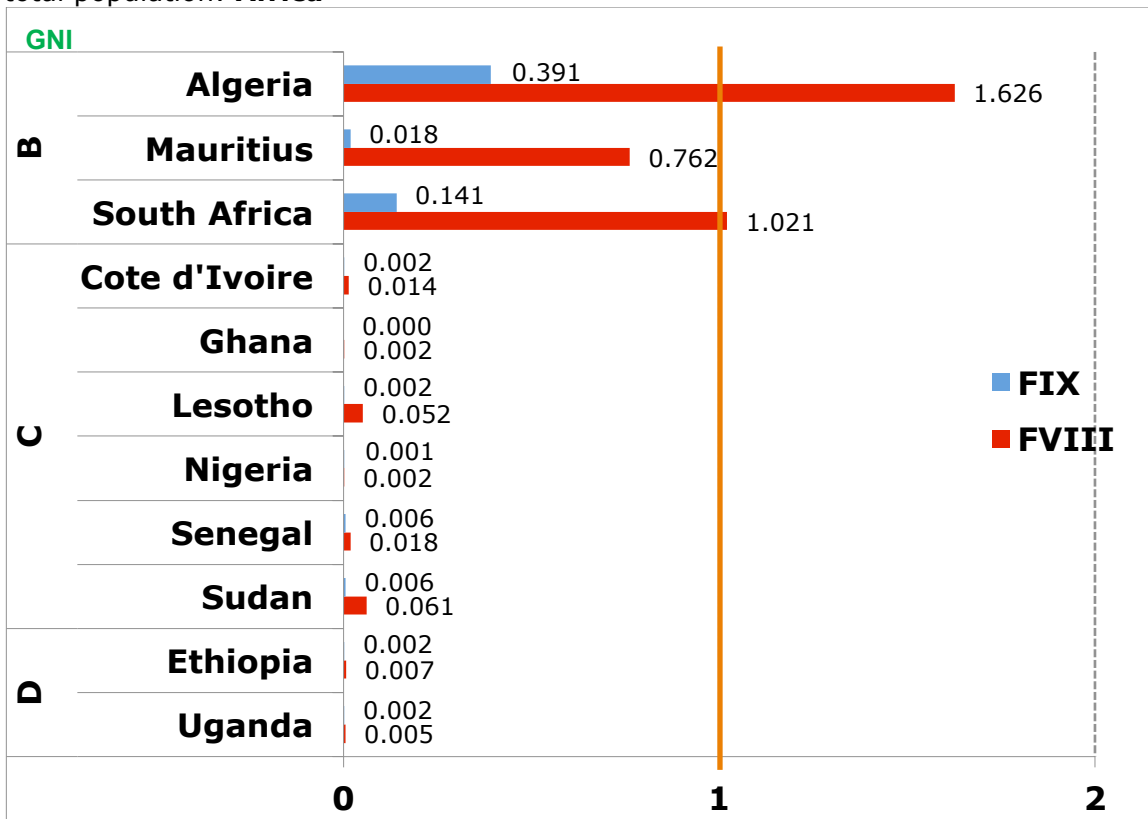


B2. Average global factor VIII use per patient based on World Bank rankings.



(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 VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **Africa**

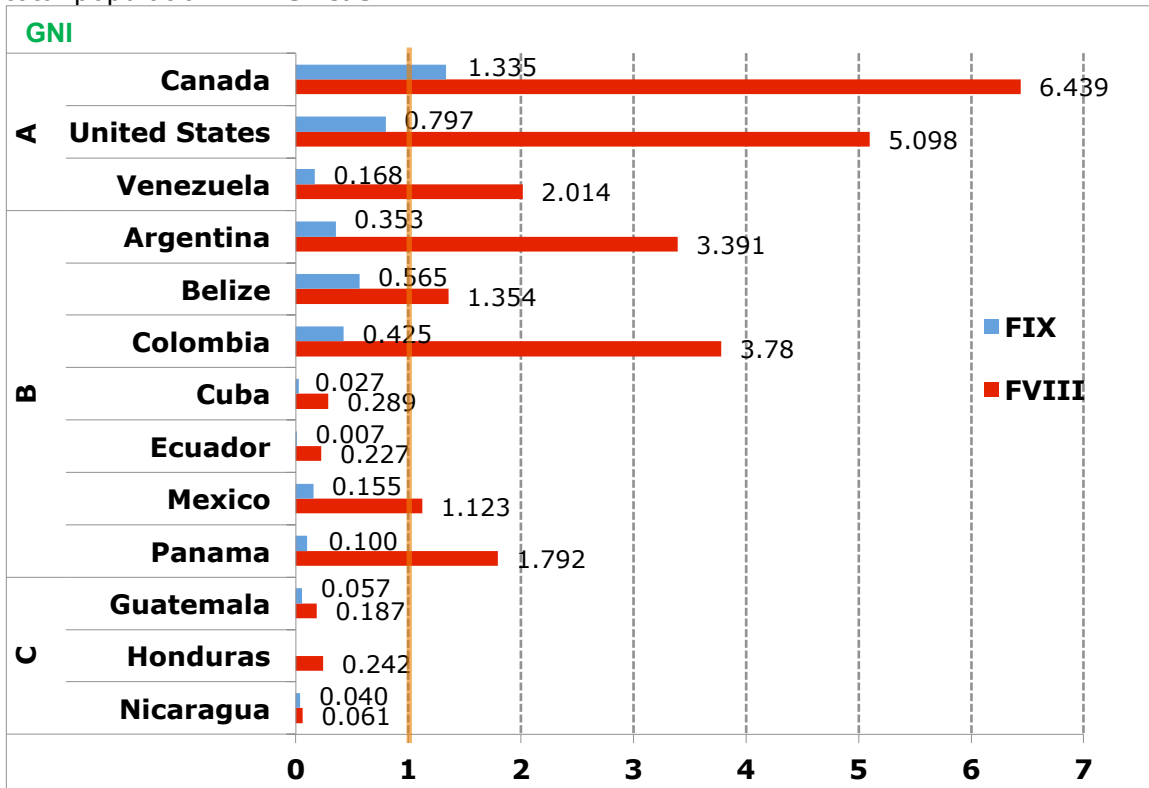


Economic category based on World Bank rankings. Categories are based on the rankings for 2012. (GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,945; B upper middle income, \$3,946 - \$12,195; and A high income, \$12,196 or more.)

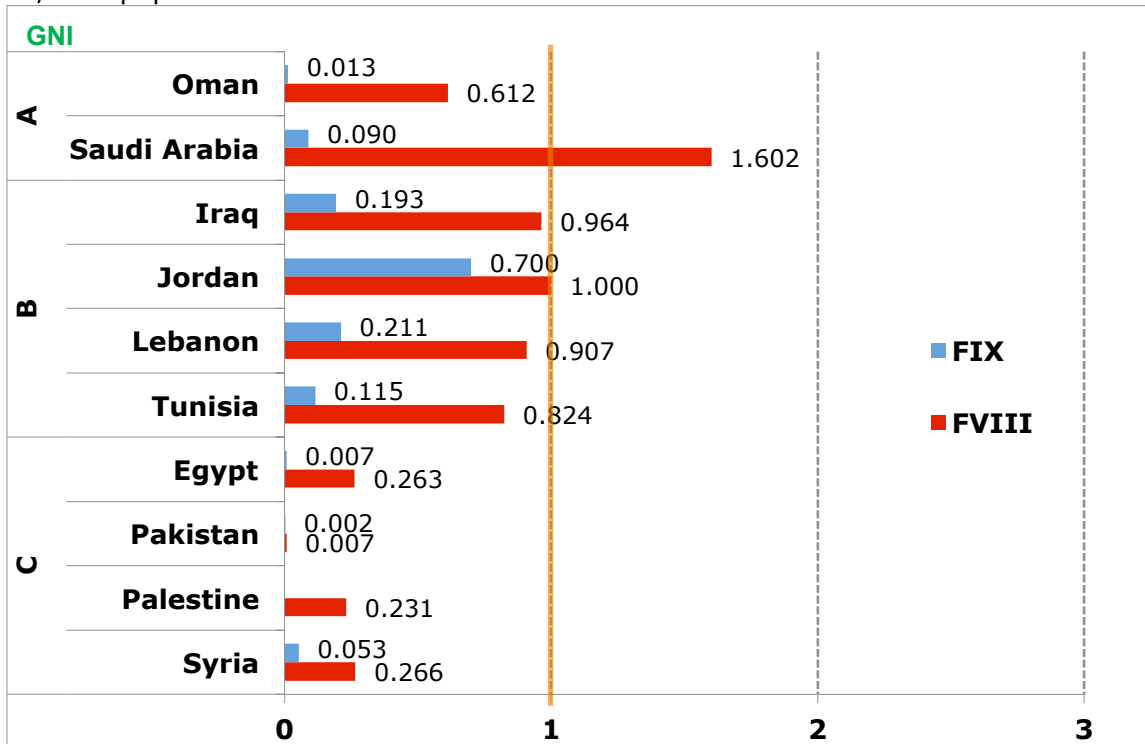
PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to 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 2012 questionnaire are included in these charts.



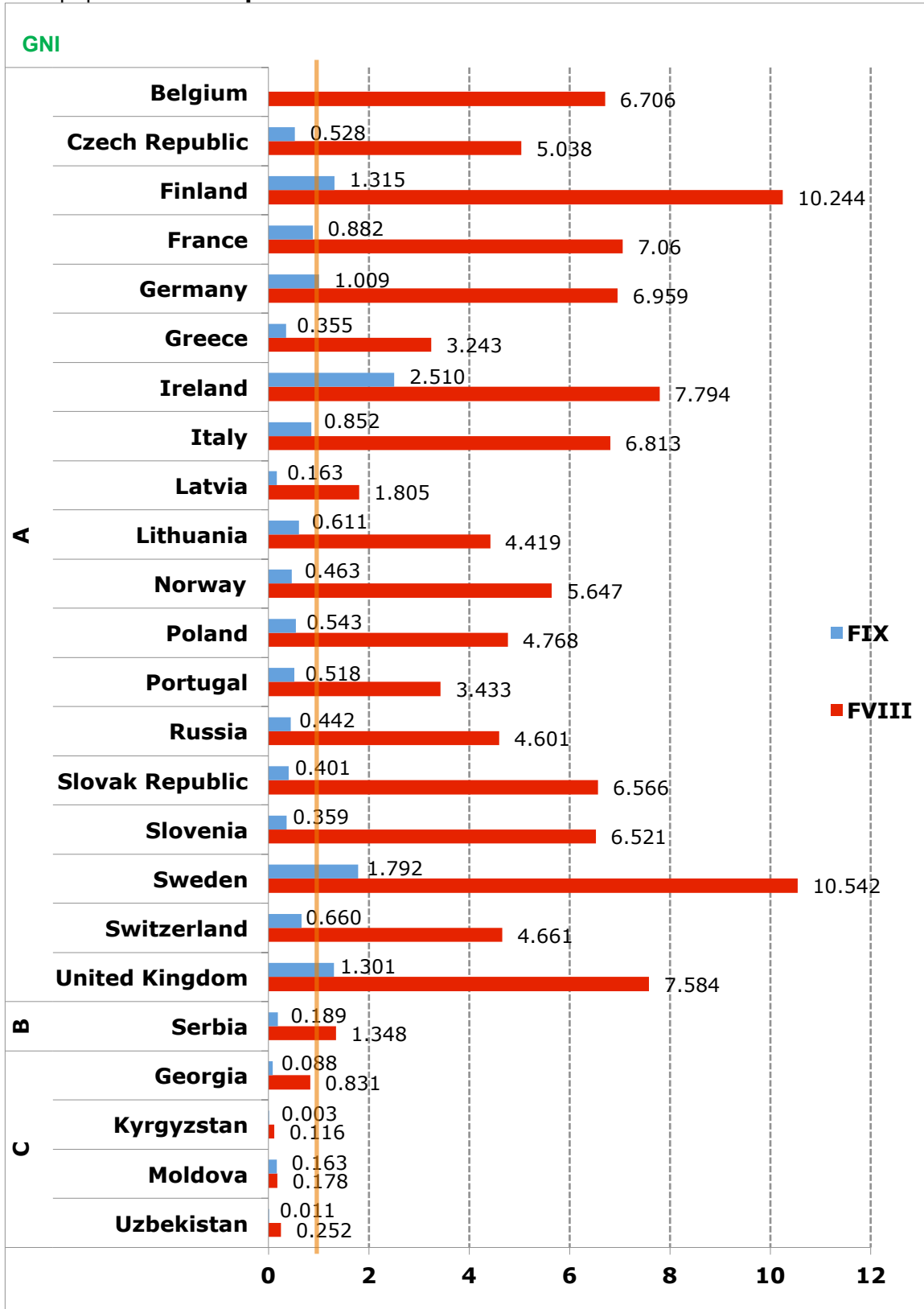
C2. Mean per capita factor VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **Americas**



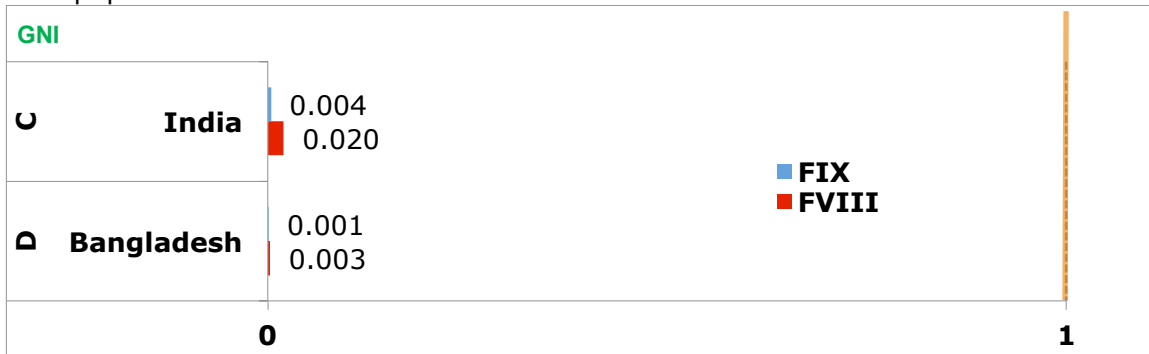
C3. Mean per capita factor VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **Eastern Mediterranean**



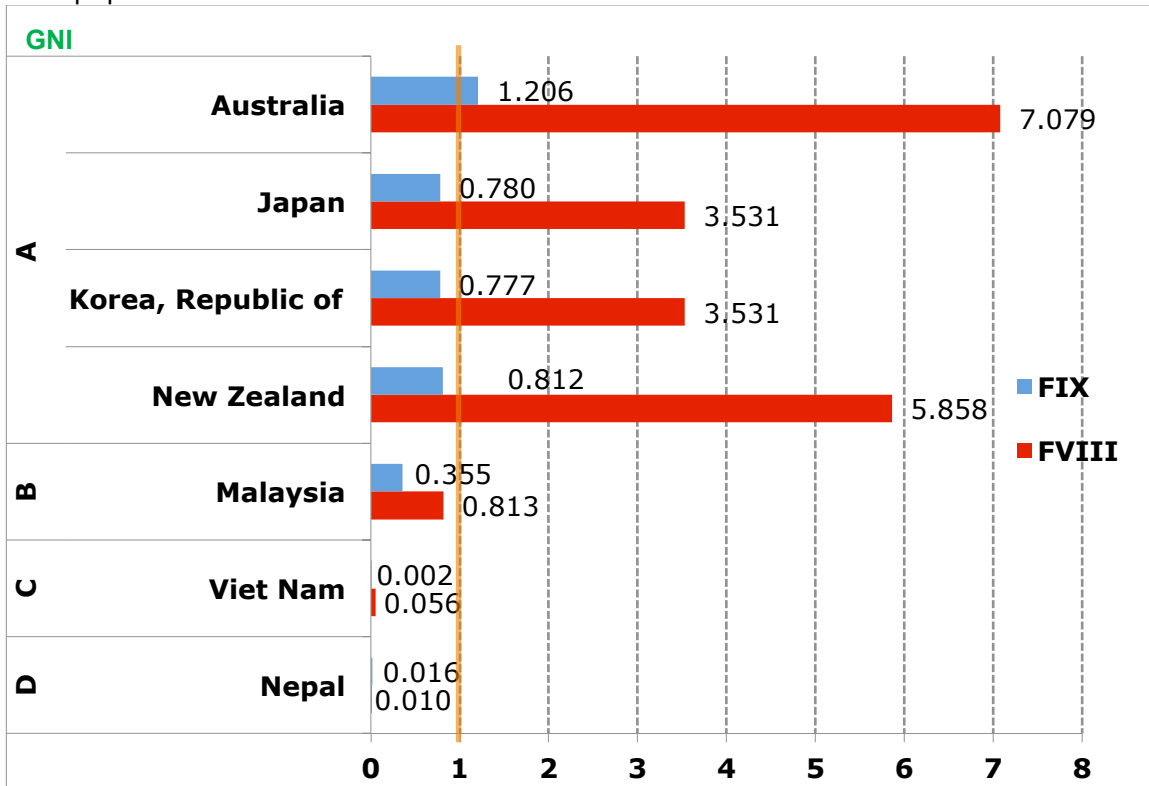
C4. Mean per capita factor VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **Europe**



C5. Mean per capita factor VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **South-East Asia**



C6. Mean per capita factor VIII and IX use in 2012 – regional and GNI comparisons of IU/total population: **Western Pacific**



Economic category based on World Bank rankings. Categories are based on the rankings for 2012. (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 2012 questionnaire are included in these charts.

## Countries included in the 2012 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 2012 survey report, 86 countries submitted data for 2012. The data used from other years is as follows. 2011: 14 countries, 2010: 5 countries, 2009: 4 countries. For countries that did not complete a 2012 survey form but are part of the WFH GAP program, WFH data on the total number of patients identified and factor use in 2012 was used. All other data are from the year indicated. 2009 to 2011 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2012 only.

Albania	2011	Greece	2012	Palestine	2012
Algeria	2012	Guatemala	2012	Panama	2012
Argentina	2012	Honduras	2012	Paraguay	2009
Armenia	2009	Hungary	2011	Peru	2010
Australia	2012	India	2012	Philippines	2011
Austria	2011	Indonesia	2012	Poland	2012
Azerbaijan	2011	Iran	2012	Portugal	2012
Bahrain	2012	Iraq	2012	Qatar	2012
Bangladesh	2012	Ireland	2012	Romania	2011
Belarus	2010	Israel	2010	Russia	2012
Belgium	2012	Italy	2012	Saudi Arabia	2012
Belize	2012	Jamaica	2012	Senegal	2012
Bolivia	2011	Japan	2012	Serbia	2012
Brazil	2012	Jordan	2012	Slovak Rep.	2012
Bulgaria	2011	Kenya	2012	Slovenia	2012
Cambodia	2012	Korea, Rep.	2012	South Africa	2012
Cameroon	2012	Kuwait	2011	Spain	2011
Canada	2012	Kyrgyzstan	2012	Sri Lanka	2010
Chile	2009	Latvia	2012	Sudan	2012
China	2012	Lebanon	2012	Sweden	2012
Colombia	2012	Lesotho	2012	Switzerland	2012
Costa Rica	2012	Lithuania	2012	Syria	2012
Cote d'Ivoire	2012	Macedonia	2011	Tanzania	2012
Cuba	2012	Malaysia	2012	Thailand	2011
Czech Rep.	2012	Mauritius	2012	Tunisia	2012
Denmark	2011	Mexico	2012	Turkey	2012
Dominican Rep.	2012	Moldova	2012	Uganda	2012
Ecuador	2012	Mongolia	2010	Ukraine	2012
Egypt	2012	Morocco	2012	United Kingdom	2012
El Salvador	2012	Nepal	2012	United States	2012
Eritrea	2012	Netherlands	2012	Uruguay	2009
Ethiopia	2012	New Zealand	2012	Uzbekistan	2012
Finland	2012	Nicaragua	2012	Venezuela	2012
France	2012	Nigeria	2012	Viet Nam	2012
Georgia	2012	Norway	2012	Zimbabwe	2011
Germany	2012	Oman	2012		
Ghana	2012	Pakistan	2012		

**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 2012. For countries that did not report population statistics for 2012 but did report during the years 2009-2011, we used the most recent number of patients reported. 2009 to 2011 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2012 only.)

<b>Country</b>	<b>Population</b>	<b>People with hemophilia</b>	<b>People with von Willebrand disease</b>	<b>People with other bleeding disorders</b>
Albania	3,002,859	292	2	Not Known
<b>Algeria</b>	37,367,226	1,918	102	137
<b>Argentina</b>	42,192,494	2,380	391	28
Armenia	2,970,495	208	10	10
<b>Australia</b>	22,015,576	2,860	2,068	773
Austria	8,219,743	645	37	35
Azerbaijan	9,493,600	1,163	200	80
<b>Bahrain</b>	1,248,348	27	Not Known	10
<b>Bangladesh</b>	161,083,804	571	0	8
Belarus	9,643,566	745	171	45
<b>Belgium</b>	10,438,353	1,020	1,612	350
<b>Belize</b>	327,719	15	Not Known	Not Known
Bolivia	10,290,003	96	2	1
<b>Brazil</b>	199,321,413	10,710	5,445	1,721
Bulgaria	7,037,935	618	90	33
<b>Cambodia</b>	14,952,665	83	1	2
<b>Cameroon</b>	20,129,878	118	1	0
<b>Canada</b>	34,300,083	3,657	3,963	1,693
Chile	17,067,369	1,252	Not Known	Not Known
<b>China</b>	1,343,239,923	11,108	58	261
<b>Colombia</b>	45,239,079	1,807	239	163
<b>Costa Rica</b>	4,636,348	204	66	Not Known
<b>Cote d'Ivoire</b>	21,952,093	66	3	3
<b>Cuba</b>	11,075,244	415	175	2,658
<b>Czech Republic</b>	10,177,300	1,031	478	49
Denmark	5,543,453	477	341	87
<b>Dominican Rep.</b>	10,088,598	262	71	123
<b>Ecuador</b>	15,223,680	104	35	3
<b>Egypt</b>	83,688,164	4,948	487	1,139
<b>El Salvador</b>	6,090,646	139	39	21

<b>Country</b>	<b>Population</b>	<b>People with hemophilia</b>	<b>People with von Willebrand disease</b>	<b>People with other bleeding disorders</b>
<b>Eritrea</b>	6,086,495	60	Not Known	Not Known
<b>Ethiopia</b>	91,195,675	61	20	0
<b>Finland</b>	5,262,930	436	3,016	42
<b>France</b>	65,630,692	6,035	1,496	413
<b>Georgia</b>	4,570,934	272	28	16
<b>Germany</b>	81,305,856	4,660	4,450	Not Known
<b>Ghana</b>	24,652,402	90	1	Not Known
<b>Greece</b>	10,767,827	912	836	246
<b>Guatemala</b>	14,099,032	119	13	1
<b>Honduras</b>	8,296,693	203	3	5
Hungary	9,958,453	Not Known	Not Known	Not Known
<b>India</b>	1,205,073,612	13,314	382	272
<b>Indonesia</b>	248,645,008	1,593	1	Not Known
<b>Iran</b>	78,868,711	5,369	1,212	2,719
<b>Iraq</b>	31,129,225	1,004	250	229
<b>Ireland</b>	4,722,028	775	629	1,500
Israel	7,590,758	540	4	1
<b>Italy</b>	61,261,254	4,529	2,233	1,805
<b>Jamaica</b>	2,889,187	Not Known	Not Known	Not Known
<b>Japan</b>	127,368,088	5,617	1,035	635
<b>Jordan</b>	6,508,887	335	215	245
<b>Kenya</b>	43,013,341	642	33	27
<b>Korea, Rep. of</b>	48,860,500	1,944	98	106
Kuwait	2,646,314	Not Known	Not Known	Not Known
<b>Kyrgyzstan</b>	5,496,737	342	8	Not Known
<b>Latvia</b>	2,191,580	145	103	5
<b>Lebanon</b>	4,140,289	165	104	69
<b>Lesotho</b>	1,930,493	22	Not Known	Not Known
<b>Lithuania</b>	3,525,761	166	302	17
Macedonia	2,082,370	315	Not Known	Not Known
<b>Malaysia</b>	29,179,952	1,218	489	364
<b>Mauritius</b>	1,313,095	52	1	7
<b>Mexico</b>	114,975,406	4,356	221	26
<b>Moldova</b>	3,656,843	224	5	5
Mongolia	3,179,997	75	4	Not Known
<b>Morocco</b>	32,309,239	40	0	0



<b>Country</b>	<b>Population</b>	<b>People with hemophilia</b>	<b>People with von Willebrand disease</b>	<b>People with other bleeding disorders</b>
<b>Nepal</b>	29,890,686	443	1	13
<b>Netherlands</b>	16,730,632	1,210	2,500	46
<b>New Zealand</b>	4,327,944	421	195	31
<b>Nicaragua</b>	5,727,707	215	63	9
<b>Nigeria</b>	170,123,740	157	6	Not Known
<b>Norway</b>	4,707,270	446	903	71
<b>Oman</b>	3,090,150	116	333	325
<b>Pakistan</b>	190,291,129	1,705	530	437
<b>Palestine</b>	4,332,801	140	Not Known	59
<b>Panama</b>	3,510,045	272	430	37
Paraguay	6,541,591	448	1	1
Peru	29,549,517	743	144	17
Philippines	103,775,002	1,131	29	Not Known
<b>Poland</b>	38,415,284	2,638	1,387	381
<b>Portugal</b>	10,781,459	645	49	65
<b>Qatar</b>	1,951,591	38	18	12
Romania	21,848,504	1,610	348	9
<b>Russia</b>	142,517,670	5,421	1,254	954
<b>Saudi Arabia</b>	26,534,504	326	75	36
<b>Senegal</b>	12,969,606	154	1	7
<b>Serbia</b>	7,276,604	488	239	23
<b>Slovak Republic</b>	5,483,088	577	570	912
<b>Slovenia</b>	1,996,617	204	162	100
<b>South Africa</b>	48,810,427	2,011	594	212
Spain	47,042,984	1,953	710	211
Sri Lanka	21,481,334	664	Not Known	Not Known
<b>Sudan</b>	34,206,710	710	191	185
<b>Sweden</b>	9,103,788	1,014	1,474	332
<b>Switzerland</b>	7,925,517	701	137	88
<b>Syria</b>	22,530,746	562	65	63
<b>Tanzania</b>	46,912,768	63	Not Known	1
Thailand	67,091,089	1,260	69	53
<b>Tunisia</b>	10,732,900	380	82	Not Known
<b>Turkey</b>	79,749,461	4,895	854	1,430
<b>Uganda</b>	33,640,833	28	2	Not Known
<b>Ukraine</b>	44,854,065	2,188	469	11

<b>Country</b>	<b>Population</b>	<b>People with hemophilia</b>	<b>People with von Willebrand disease</b>	<b>People with other bleeding disorders</b>
<b>United Kingdom</b>	63,047,162	6,742	9,697	8,355
<b>United States</b>	313,847,465	18,628	8,035	1,796
Uruguay	3,316,328	236	316	11
<b>Uzbekistan</b>	28,394,180	1,301	93	27
<b>Venezuela</b>	28,047,938	2,350	787	860
<b>Viet Nam</b>	91,519,289	2,250	52	181
Zimbabwe	12,619,600	320	Not Known	Not Known
<b>Total</b>	<b>6,419,691,046</b>	<b>172,373</b>	<b>66,144</b>	<b>35,549</b>

**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 2012.)

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					
<b>Algeria</b>	1,566	352		102	21	3	13	15	56	4	3	9		15		
<b>Argentina</b>	2,075	305	180	391				9			1		15	1		2
Armenia	184	18		10	5				2	2	1			1		
<b>Australia</b>	2,316	544		2,068	29		15		53	18	170	18	246	14	2	208
Austria	546	99	0	37	0	0	5	1	12	3	7	3				0
Azerbaijan	1,065	98		200			5	11	12	10	3	2	37		6	
<b>Bahrain</b>	23	2	0		0	3	2	2	1	5	0	3	0	6		
<b>Bangladesh</b>	494	77	6	0	1							1				
Belarus	452	94		171					14	1	26	4				
<b>Belgium</b>	830	190	8	1,612	1	1	24	2	78	6	112	4	95	19	1	7
<b>Belize</b>	10	5														
Bolivia	84	10		2					1				131			
<b>Brazil</b>	9,122	1,801		5,445	52	11	112	17	485	73	129	41	285	181	41	294
Bulgaria	560	68		90		1			5	3	2	3	8	11		
<b>Cambodia</b>	71	12		1								1		1		2
<b>Cameroon</b>	112	5	0	1	0	0	0	0			0		0	0	0	0
<b>Canada</b>	2,966	691	0	3,963	122	13	59	4	277	37	363	54	11	55	30	668
Chile	1,068	184														
<b>China</b>	9,675	1,433		58			2		2	1	2	1				
<b>Colombia</b>	1,497	310	167	239	21	9	9	2	17	1	11	7	37	6	5	38
<b>Costa Rica</b>	172	32		66												
<b>Cote d'Ivoire</b>	61	5	0	3	0	0	0	0	0	2	1	0	0	0	0	0
<b>Cuba</b>	346	69		175	2	1	2	0	0	0	12	7	10	2	0	2,622
<b>Czech Republic</b>	898	133	0	478												
Denmark	384	91		341	1	1	2		4	7	5	11		8	7	43
<b>Dominican Rep.</b>	223	37	123	71					7	22		3	4	3		
<b>Ecuador</b>	98	6		35			1					1		1		
<b>Egypt</b>	3,960	988		487	132	8	157	7	95	105	92	29		412	10	
<b>El Salvador</b>	120	19	0	39	0	0	0		2	1	5	0				
<b>Eritrea</b>	54	6														
<b>Ethiopia</b>	51	10	75	20												
<b>Finland</b>	339	97		3,016	3	1	5		10	7	2	13				
<b>France</b>	4,937	1,098	0	1,496	37	1	44	11	135	18	142	25	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
<b>Georgia</b>	230	40		28					2			2	7			6
<b>Germany</b>	3,910	750		4,450												
<b>Ghana</b>	87	3		1												
<b>Greece</b>	761	151		836	19	1	16		74	6	70	12		15	11	22
<b>Guatemala</b>	109	10		13					1				1	1		
<b>Honduras</b>	180	23		3					3		1	1				
Hungary																
<b>India</b>	11,517	1,797		382	7	5	24	55	31	25	29	62		34		
<b>Indonesia</b>	477	66	1,049	1									1			
<b>Iran</b>	4,438	931	0	1,212	107	24	147	190	470	153	152	205	478	467	86	254
<b>Iraq</b>	766	273		229	40	1	8	2	55	12	10	29				100
<b>Ireland</b>	547	228	0	629	0	1	131	0	103	58	141	8	846	8	3	201
Israel	458	92		4												
<b>Italy</b>	3,779	750	0	2,233	0	20	132	30	595	96	372	41	59			207
<b>Jamaica</b>																
<b>Japan</b>	4,627	990		1,035	62	7	33	9	72	20	32	60	26			
<b>Jordan</b>	255	80		215		4	13		45	25	42	12		103	1	
<b>Kenya</b>	428	86		33									14			
<b>Korea, Rep.</b>	1,579	365		98	6		4	7	32	2	17	3				
Kuwait																
<b>Kyrgyzstan</b>	332	10		8												
<b>Latvia</b>	121	24	0	103	0	0	0	0	5	0	0	0	0			
<b>Lebanon</b>	130	35	0	104	34	0	9	1	7	5	5	2	0	1	0	5
<b>Lesotho</b>	20	2														
<b>Lithuania</b>	146	20		302					11	2		2				
Macedonia	210	105														
<b>Malaysia</b>	1,037	181		489	1	2	18	1	44	15	44	14		43	0	37
<b>Mauritius</b>	48	4		1					3	1	1					2
<b>Mexico</b>	3,793	563	334	221			3	1	14	4	2	1		1		
<b>Moldova</b>	207	17		5					1		4					
Mongolia	62	13		4												
<b>Morocco</b>	36	4	0							4	0					
<b>Nepal</b>	388	56		1		1	1		1	7		2				
<b>Netherlands</b>	1,026	184		2,500	0	2	4		9	0	1	11	3	16		
<b>New Zealand</b>	346	76	0	195	0	1	0	0	6	1	3	1	13	1	0	5
<b>Nicaragua</b>	170	25	20	63	6								1	2		
<b>Nigeria</b>	154	3		6												
<b>Norway</b>	342	104	0	903	2	2	3	0	24	0	1	4	0	9	2	8
<b>Oman</b>	109	7		333	4	1	7	5	56	4	23	1	19	26	2	177
<b>Pakistan</b>	1,412	293		530	26	2	24	8	50	26	3	35	55	95	10	103



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
<b>Palestine</b>	113	27					1			3						56
<b>Panama</b>	244	31	0	430	0	0	0	0	8	14	0	0	0	3	1	12
Paraguay	434	14		1					1							
Peru	577	103	63	144			1		8		5	1		1		0
Philippines	945	145	41	29												
<b>Poland</b>	2,261	377		1,387	17	0	25	3	214	19	39	10	0	19	5	30
<b>Portugal</b>	535	110		49	1		3		2	1	7	1	43	1		6
<b>Qatar</b>	34	4		18					1		2	4		6	0	2
Romania	1,415	195	15	348		1		2	5		1					
<b>Russia</b>	4,720	701		1,254									954			
<b>Saudi Arabia</b>	260	66	0	75	0	2	3	1	6	1	9	13	0	66	2	0
<b>Senegal</b>	141	13	0	1	0	0	1	0	3	0	0	0	0	0	0	3
<b>Serbia</b>	421	72	0	239	2	0	0	1	10	0	5	3	1	0	1	0
<b>Slovak Republic</b>	505	72		570	76	0	65	2	640	30	48	3		10	15	23
<b>Slovenia</b>	183	21		162			9	2	11		17	1		3		
<b>South Africa</b>	1,696	315		594	7	0	44	5	18	9	30	8		17	23	51
Spain	1,679	277		710	15	3	13	3	25	9	24	17	152	15		
Sri Lanka	498	137	29													
<b>Sudan</b>	604	106		191	19		29	0	20	15		27		75		
<b>Sweden</b>	817	197		1,474		4	1	1	227	20	63	7	1	8	6	250
<b>Switzerland</b>	587	117	0	137	18	0	4	4	29	4	18	14	0	0	0	0
<b>Syria</b>	562	65		65	14		5	28	9	3				11		
<b>Tanzania</b>	35	7	22													
Thailand	294	51		69	1	0	2	1	14	1	0	0	0			
<b>Tunisia</b>	300	70	0	82	24	1	14	6	31	6	12	15	6	62	8	5
<b>Turkey</b>	4,132	763		854			28		537	122	24	106	555			20
<b>Uganda</b>	20	4	4	2												
<b>Ukraine</b>	1,860	328		469										1		
<b>United Kingdom</b>	5,571	1,171		9,697	174	13	148	23	833	197	2,217	61		116	65	1,525
<b>United States</b>	14,516	4,112		8,035	63	17	94	9	477	65	284	67		103	13	1,746
Uruguay	185	30	21	316	1		2		3	1	2		2	1	1	
<b>Uzbekistan</b>	1,201	100		93	1	2			8		9		25	8		15
<b>Venezuela</b>	1,844	506		787	19	65	30	27	125	104	327	16	12	15	4	135
<b>Viet Nam</b>	1,863	397		52	4	3	4	7	17	11	6	4	39	80		
Zimbabwe	303	16	1													
<b>Total</b>	<b>142,205</b>	<b>28,008</b>	<b>2,158</b>	<b>66,123</b>	<b>1,197</b>	<b>238</b>	<b>1,560</b>	<b>515</b>	<b>6,264</b>	<b>1,427</b>	<b>5,192</b>	<b>1,126</b>	<b>4,192</b>	<b>2,179</b>	<b>361</b>	<b>8,890</b>

**Gender distribution**

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

<b>Disorder</b>	<b>Countries reporting</b>	<b>Total patients identified</b>	<b>Male</b>	<b>Percent male</b>	<b>Female</b>	<b>Percent female</b>	<b>Gender not known</b>	<b>Percent not known</b>
<b>Hemophilia A</b>	106	142,205	129,708	91	2,344	2	10,153	7
<b>Hemophilia B</b>	106	28,008	25,850	92	719	3	1,439	5
<b>Hemophilia type unknown</b>	39	2,158	2,013	93	22	1	123	6
<b>Von Willebrand disease</b>	95	66,123	22,637	35	33,297	50	10,189	15
<b>Factor I deficiency</b>	55	1,197	442	37	534	45	221	18
<b>Factor II deficiency</b>	51	238	112	47	94	40	32	13
<b>Factor V deficiency</b>	62	1,560	580	37	703	45	277	18
<b>Factor V+VIII deficiency</b>	49	515	289	56	197	38	29	6
<b>Factor VII deficiency</b>	74	6,264	2,796	45	2,697	43	771	12
<b>Factor X deficiency</b>	65	1,427	631	44	596	42	200	14
<b>Factor XI deficiency</b>	65	5,151	2,123	41	2,565	50	463	9
<b>Factor XIII deficiency</b>	67	1,126	586	52	392	35	148	13
<b>Bleeding disorder: type unknown</b>	48	4,192	2,078	49	958	23	1,156	28
<b>Platelet disorders: Glanzmanns thrombasthenia</b>	57	2,179	776	36	786	36	617	28
<b>Platelet disorders: Bernard Soulier syndrome</b>	36	361	148	41	173	48	40	11
<b>Platelet disorders: other or unknown</b>	44	8,890	2,358	27	4,291	48	2,241	25

**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	75	No data
Argentina	286	11
Australia	75	1
Bahrain	0	0
Bangladesh	1	No data
Brazil	682	31
Cameroon	8	0
Canada	92	4
China	84	3
Colombia	63	5
Costa Rica	19	1
Cote d'Ivoire	1	0
Cuba	34	0
Czech Rep.	13	2
Dominican Republic	5	0
Ecuador	1	0
Egypt	31	2
El Salvador	6	0
France	115	3
Georgia	4	No data
Germany	90	15
Greece	20	3
Guatemala	2	No data
Honduras	3	No data
India	607	3
Iran	259	11
Iraq	50	2
Ireland	6	2
Italy	417	8
Jamaica	4	0
Japan	87	19
Jordan	17	1
Latvia	2	2
Lebanon	6	0
Lesotho	1	0
Lithuania	5	0

Country	Hemophilia A w/ clinically identified inhibitors	Hemophilia B w/ clinically identified inhibitors
Malaysia	93	3
Mauritius	0	0
Mexico	185	11
Moldova	0	0
Morocco	1	0
New Zealand	14	0
Nicaragua	2	No data
Norway	10	0
Oman	17	0
Pakistan	42	3
Palestine	2	No data
Panama	13	0
Poland	150	4
Russia	200	2
Saudi Arabia	42	2
Senegal	4	0
Serbia	22	0
Slovak Republic	5	0
Slovenia	2	No data
South Africa	165	11
Sudan	7	1
Sweden	21	4
Switzerland	8	1
Syria	35	1
Tunisia	7	No data
Turkey	124	15
Uganda	0	0
Ukraine	74	3
United Kingdom	225	10
United States	860	101
Uzbekistan	33	No data
Venezuela	93	3
Viet Nam	48	2
<b>Totals</b>	<b>5675</b>	<b>306</b>

**Age distribution: hemophilia A** (76 countries reported age data.)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Algeria	97	168	592	512	197	1,566
Argentina	145	347	224	900	410	49
Australia	129	262	155	883	887	
Bahrain	4	4	4	10	1	0
Bangladesh	22	145	118	183	26	0
Belgium	25	111	68	281	342	3
Belize		6	2	2		
Brazil	463	1,614	1,127	4,448	1,425	45
Cambodia	21	35	7	8		
Cameroon	35	25	34	17	1	
Canada	156	415	248	1,210	937	
China	393	2,170	1,074	4,709	1,206	123
Colombia	142	149	485	142	42	537
Costa Rica	8	38	23	80	23	
Cote d'Ivoire	9	15	20	13	4	0
Cuba	12	44	54	190	46	
Czech Republic	41	101	62	384	310	0
Ecuador	0		4	53	10	31
Egypt	1,423	210	73	306	35	1,916
El Salvador	18	62	40			
Eritrea	1	17	8	20	3	5
Ethiopia	9	21	12	9	0	0
France	271	796	464	2,116	1,290	0
Georgia	32	40	25	111	24	
Ghana	15	48	13	11		
Greece	21	85	43	325	265	22
Guatemala						109
Honduras	20	55	43	47	3	11
India	350	1,934	1,301	4,059	670	3,203
Iran	196	644	376	2,573	637	112
Iraq	158	282	146	160	20	
Ireland	34	96	44	221	152	0
Italy						3,779
Kenya	121	139	67	61	40	
Korea, Republic of	69	225	171	863	251	0
Kyrgyzstan						332
Latvia	7	15	6	61	31	1
Lebanon	10	25	11	65	17	2



<b>Country</b>	<b>0-4</b>	<b>5-13</b>	<b>14-18</b>	<b>19-44</b>	<b>45+</b>	<b>Age not known</b>
Lesotho		6	8	6		
Lithuania						146
Malaysia	252	216	52	82	26	409
Mauritius	2	10	9	17	9	1
Mexico	104	643	485	1,526	320	715
Moldova	1	18	7	92	89	
Morocco	4	12	6	13	1	0
Nepal	6	120	80	159	40	
Netherlands	8	156	93	250	437	82
New Zealand	15	61	29	125	69	46
Nicaragua	9	32	29	88	10	23
Nigeria	17	58	45	33	2	
Norway	18	39	19	143	119	0
Oman	13	31	7	52	6	
Pakistan	250	522	353	281	31	
Palestine	5	26	21	43	7	11
Panama	12	41	8	142	41	
Poland	40	178	120	1,196	726	1
Portugal	15	56	33	225	161	45
Qatar	4	17	13			
Russia						4,720
Saudi Arabia	56	92	51	59		
Senegal	14	53	19	51	4	
Serbia	28	50	30	186	122	5
Slovak Republic	20	53	30	239	163	
Slovenia	6	18	4	93	62	
South Africa	53	276	210	758	355	44
Sudan	55	197	106	211	17	18
Sweden	34	116	45	126	121	
Switzerland	4	69	42	230	242	0
Syria	66	165	92	205	27	7
Turkey	257	943	593	1,794	545	0
Uganda	9	8	1	2	0	
Ukraine			473	1,387		
United Kingdom	356	712	472	2,147	1,881	3
Uzbekistan	31	165	196	502	44	50
Venezuela	82	287	173	629	211	124
Viet Nam	163	390	254	851	153	76
<b>Totals</b>	<b>6,466</b>	<b>16,179</b>	<b>11,352</b>	<b>38,976</b>	<b>15,346</b>	<b>18,372</b>

**Age distribution: hemophilia B** (77 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Algeria	54	60	71	98	69	352
Argentina	22	63	42	118	54	6
Australia	18	69	28	228	201	
Bahrain	0	0	0	2	0	0
Bangladesh	6	26	24	19	2	0
Belgium	4	21	12	64	86	3
Belize		2	1	2		
Brazil	93	340	247	812	306	3
Cambodia	6	2	2	2		
Cameroon	3		2			
Canada	36	66	64	280	245	
China	57	273	150	713	231	9
Colombia	40	25	101	28	28	98
Costa Rica	2	5	5	17	3	
Cote d'Ivoire	0	0	2	2	1	0
Cuba	2	11	7	36	13	
Czech Republic	7	13	9	55	49	0
Ecuador	0	0	1	5	0	
Egypt	324	39	14	59	7	544
El Salvador	2	12	5			
Eritrea			2	3		1
Ethiopia	2	2	1	3	0	0
France	64	186	104	464	280	0
Georgia	5	4	3	18	10	
Ghana		2		1		
Greece	4	8	7	72	54	6
Guatemala						10
Honduras		2		21		
India	50	296	225	661	124	441
Indonesia	4	17	7	23	1	11
Iran	29	116	78	585	121	2
Iraq	41	95	65	53	19	
Ireland	12	41	15	101	59	0
Italy						750
Kenya	5	19	31	29	2	
Korea, Republic of	20	68	44	177	56	0
Kyrgyzstan						10
Latvia	1	2	1	16	4	0

Country	0-4	5-13	14-18	19-44	45+	Age not known
Lebanon	1	9	5	15	5	
Lesotho	1	1				
Lithuania						20
Malaysia	66	46	7	28	4	30
Mauritius		2		2		
Mexico	16	87	76	247	52	85
Moldova	0	1	0	11	5	
Morocco	1	1	0	2	0	0
Nepal	14	13	3	17	4	
Netherlands	1	24	19	55	69	16
New Zealand	2	7	4	32	24	7
Nicaragua	1	2	1	16	2	2
Nigeria		1	1	1		
Norway	8	16	9	36	39	0
Oman	1	2	0	4	0	
Pakistan	44	103	81	66	0	
Palestine	1	11	4	9	2	0
Panama	2	10	4	13	2	
Poland	7	34	22	201	110	3
Portugal	1	11	7	46	35	10
Qatar		1	2	1		
Russia						701
Saudi Arabia	4	26	4	28		
Senegal	3	7	1	1	1	
Serbia	6	14	5	34	13	0
Slovak Republic	6	10	5	36	15	
Slovenia		1	1	10	9	
South Africa	20	59	24	137	71	4
Sudan	17	40	18	30		1
Sweden	9	23	11	40	55	
Switzerland	4	6	8	49	50	0
Syria	2	22	15	23	1	2
Turkey	51	188	110	319	95	0
Uganda	1	3	0	0	0	
Ukraine			80	248		
United Kingdom	81	136	83	499	372	0
Uzbekistan	5	19	13	56	4	3
Venezuela	14	61	36	160	76	93
Viet Nam	28	60	54	189	34	15
<b>Totals</b>	<b>1,331</b>	<b>2,942</b>	<b>2,083</b>	<b>7,428</b>	<b>3,174</b>	<b>3,238</b>

**Age distribution: VWD** (76 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Algeria					102	
Argentina	0	18	16	195	105	57
Australia	39	224	164	876	765	
Bahrain						0
Bangladesh	0	0	0	0	0	0
Belgium	25	309	127	662	476	13
Brazil	57	638	628	2,764	1,333	25
Cambodia		1				
Cameroon	1					
Canada	39	390	367	1,935	1,232	
China	1	15	7	29	6	0
Colombia	6	45	2	88	10	88
Cote d'Ivoire	0	0	0	3	0	0
Cuba	0	16	28	88	43	
Czech Republic	5	35	17	233	188	0
Dominican Republic						71
Ecuador	0	3	5	16	5	6
Egypt	200	14	6	25	5	237
El Salvador	1	21	17			
Ethiopia	0	0	2	17	1	0
Finland						3,016
France	34	260	128	586	488	0
Georgia		3	1	17	7	
Ghana		1				
Greece	5	133	80	372	246	
Guatemala						13
Honduras			1	2		
India	8	66	40	153	15	100
Indonesia			1			
Iran	49	251	117	648	139	8
Iraq	45	62	93	25	4	21
Ireland	0	0	18	419	192	0
Italy						2,233
Japan						1,035
Jordan						215
Kenya	3	13	6	7		4
Korea, Republic of	1	10	19	54	14	0
Kyrgyzstan						8

Country	0-4	5-13	14-18	19-44	45+	Age not known
Latvia			2	63	34	4
Lebanon	4	24	17	46	10	3
Lithuania						302
Malaysia	59	130	39	176	23	62
Mauritius				1	0	
Mexico	5	28	27	76	13	72
Moldova	0	0	0	5	0	
Morocco	0	0	0	0	0	0
Nepal		1				
Netherlands	150	210	300	650	675	515
New Zealand	5	20	15	64	43	48
Nicaragua		5	7	3	1	47
Nigeria			2	4		
Norway	10					893
Oman						333
Pakistan	58	215	142	112	3	
Panama	6	91	185	121	27	
Poland	12	170	147	699	340	19
Portugal	0	1	4	19	23	2
Qatar						18
Russia						1,254
Saudi Arabia	4	10	34	26		1
Senegal	0	0	1	0	0	
Serbia	10	23	12	136	58	0
Slovak Republic						570
Slovenia	3	22	10	91	36	
South Africa	3	51	56	263	194	27
Sudan	36	82	30	38	5	
Sweden	6	28	21	267	264	888
Switzerland	1	10	11	52	63	0
Syria	5	23	6	26	3	2
Tunisia						82
Turkey	70	257	151	312	64	0
Uganda						2
Ukraine			87	382		
United Kingdom	314	991	752	4,129	3,508	3
Venezuela	12	131	61	306	110	167
Viet Nam	5	10	3	20	2	12
<b>Totals</b>	<b>1,297</b>	<b>5,061</b>	<b>4,012</b>	<b>17,301</b>	<b>10,875</b>	<b>12,476</b>

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

Country	Hemophilia HIV+	Hemophilia HCV+	VWD HIV+	VWD HCV+
Algeria	3	41	0	5
Argentina	63	620	0	21
Bahrain	0	0	0	0
Bangladesh	No data	1	No data	No data
Cameroon	0	0	0	No data
Canada	199	No data	No data	No data
China	32	203	0	0
Colombia	4	150	0	11
Cote d'Ivoire	0	1	0	0
Cuba	4	149	0	9
Czech Republic	2	183	0	4
Dominican Republic	0	12	0	0
Ecuador	0	0	0	0
Ethiopia	4	3	No data	No data
Finland	0	No data	No data	No data
France	456	1,730	14	151
Georgia	0	130	0	3
Germany	395	2,250	4	No data
Greece	63	305	1	26
Guatemala	0	0	0	No data
India	156	22	No data	No data
Indonesia	1	57	No data	No data
Iran	50	1,800	No data	No data
Iraq		30		35
Ireland	33	141	0	11
Italy	266	1,501	9	26
Jamaica	1	No data	No data	No data
Japan	743	1,571	7	80
Jordan	2	46	No data	No data
Kenya	23	No data	0	No data
Korea, Republic of	No data	No data	0	0
Kyrgyzstan	No data	300	No data	No data
Lebanon	0	0	0	0
Lesotho	0	0	No data	No data
Lithuania	0	No data	0	No data
Malaysia	3	168	0	0
Mauritius	0	6	0	1
Mexico	23	119	1	3
Morocco	0	0	No data	No data
Nepal	0	6	0	0
Netherlands	No data	No data	10	15
New Zealand	6	57	1	6
Nicaragua	1	17	0	0
Norway	5	No data	0	No data
Oman	2	16	No data	No data

<b>Country</b>	<b>Hemophilia HIV+</b>	<b>Hemophilia HCV+</b>	<b>VWD HIV+</b>	<b>VWD HCV+</b>
Pakistan	5	326	No data	64
Palestine	No data	2	No data	No data
Panama	18	19		1
Saudi Arabia	31	88	No data	No data
Senegal	0	No data	No data	No data
Serbia	9	125	2	12
Slovak Republic	0	140	0	23
Slovenia	7	89	0	6
South Africa	66	222	1	4
Sudan	1	6	1	38
Sweden	33	98	0	60
Syria	0	71	0	6
United Kingdom	305	712	5	72
United States	2,017	6,527	26	487
Uzbekistan	3	236		10
Venezuela	85	324	9	25
Viet Nam	1	209	0	8
<b>Totals</b>	<b>5,121</b>	<b>20,829</b>	<b>91</b>	<b>1,223</b>

**Reported Use of Factor Concentrates in 2012: 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 2012 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	60,772,500	47,115,500	13,657,000	0	1.626	1.626	78%	22%
Argentina	143,055,500	108,000,000	35,000,000	55,500	3.391	3.389	75%	24%
Australia	155,839,250	17,844,250	137,995,000		7.079	7.079	11%	89%
Bangladesh	406,466	387,440	19,026	206,466	0.003	0.001	95%	5%
Belgium	70,000,000	5,000,000	65,000,000		6.706	6.706	7%	93%
Belize	443,783	11,000	432,783	443,783	1.354	0.000	2%	98%
Canada	220,867,573	30,953,715	189,913,858	0	6.439	6.439	14%	86%
Colombia	170,996,500	105,761,500	65,235,000	149,580	3.780	3.777	62%	38%
Cote d'Ivoire	312,671	22,021	290,650	312,671	0.014	0.000	7%	93%
Cuba	3,203,023	3,175,429	27,594	106,023	0.289	0.280	99%	1%
Czech Rep.	51,276,608	32,973,006	18,303,602	0	5.038	5.038	64%	36%
Ecuador	3,460,600		0	0	0.227	0.227		
Egypt	22,000,000	16,000,000	6,000,000		0.263	0.263	73%	27%
Ethiopia	665,000	465,000	200,000	199,500	0.007	0.005	70%	30%
Finland	53,914,050	6,841,050	47,073,000		10.244	10.244	13%	87%
France	463,346,750	66,852,250	396,494,500		7.060	7.060	14%	86%
Georgia	3,800,000	50,000	50,000	50,000	0.831	0.820		
Germany	565,800,000	248,952,000	316,848,000	0	6.959	6.959	44%	56%
Ghana	40,000		40,000	40,000	0.002	0.000	0%	100%
Greece	34,917,907	2,231,513	32,686,394	0	3.243	3.243	6%	94%
Guatemala	2,631,000	3,500,000	2,631,000	76,326	0.187	0.181		
Honduras	2,005,184			205,184	0.242	0.217		
India	24,240,000	23,230,000	1,001,000	11,000	0.020	0.020	96%	4%
Iraq	30,000,000		30,000,000	0	0.964	0.964	0%	100%
Ireland	36,805,250	1,824,500	34,980,750	0	7.794	7.794	5%	95%
Italy	417,389,250	91,928,500	325,460,750	0	6.813	6.813	22%	78%
Japan	449,700,000	76,300,000	373,400,000	0	3.531	3.531	17%	83%
Jordan	6,508,887				1.000	1.000		
Kenya	361,146			361,146	0.008	0.000		
Korea, Rep.	172,546,000	70,351,000	102,195,000		3.531	3.531	41%	59%
Kyrgyzstan	640,000			300,000	0.116	0.062		
Latvia	3,955,000	3,492,000	463,000	0	1.805	1.805	88%	12%
Lebanon	3,754,326	2,100,000	970,000	684,326	0.907	0.741		
Lesotho	100,000	0	0	0	0.052	0.052		
Lithuania	15,580,000	7,381,000	8,199,000		4.419	4.419	47%	53%





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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
Malaysia	23,731,000	23,321,000	410,000		0.813	0.813	98%	2%
Mauritius	1,000,000	1,000,000	0		0.762	0.762	100%	0%
Mexico	129,120,000	115,787,750	13,332,250	238,750	1.123	1.121	90%	10%
Moldova	650,000	650,000	0	150,000	0.178	0.137	100%	0%
Nepal	288,839			230,518	0.010	0.002		
New Zealand	25,351,250	3,675,500	21,675,750	0	5.858	5.858	14%	86%
Nicaragua	350,000	350,000	0	350,000	0.061	0.000	100%	0%
Nigeria	336,508	237,708	98,800	336,508	0.002	0.000	71%	29%
Norway	26,580,000	2,710,000	23,870,000	0	5.647	5.647	10%	90%
Oman	1,890,000	0	1,890,000	0	0.612	0.612	0%	100%
Pakistan	1,320,752	245,690	1,075,062	1,056,602	0.007	0.001	19%	81%
Palestine	1,000,000				0.231	0.231		
Panama	6,290,465	6,283,215	27,500	0	1.792	1.792	100%	0%
Poland	183,162,900	130,506,400	52,656,500	0	4.768	4.768	71%	29%
Portugal	37,012,250	13,695,500	23,316,750		3.433	3.433	37%	63%
Russia	655,712,308	568,140,858	87,571,450	0	4.601	4.601	87%	13%
Saudi Arabia	42,496,000	8,499,200	33,996,800	0	1.602	1.602	20%	80%
Senegal	228,000	50,000	178,000	228,000	0.018	0.000	22%	78%
Serbia	9,812,500	9,600,000	212,500	0	1.348	1.348	98%	2%
Slovak Rep.	36,000,000	34,500,000	1,500,000	0	6.566	6.566	96%	4%
Slovenia	13,019,650	2,831,000	10,188,650		6.521	6.521	22%	78%
South Africa	49,857,000	46,616,750	3,240,250	0	1.021	1.021	94%	6%
Sudan	2,089,022	1,712,500	376,522	376,522	0.061	0.050	82%	18%
Sweden	95,970,000	15,473,000	80,497,000	0	10.542	10.542	16%	84%
Switzerland	36,942,750	6,899,850	30,046,000	0	4.661	4.661	19%	81%
Syria	6,000,000	6,000,000	0	355,000	0.266	0.251	100%	0%
Tunisia	8,845,750	6,618,750	2,227,000		0.824	0.824	75%	25%
Uganda	152,641	0	152,641		0.005	0.005	0%	100%
United Kingdom	478,121,230	53,775,170	424,346,060	0	7.584	7.584	11%	89%
United States	1,600,000,000	500,000,000	1,300,000,000		5.098	5.098		
Uzbekistan	7,157,000	7,157,000		215,000	0.252	0.244	100%	0%
Venezuela	56,500,000	20,000,000	36,500,000	0	2.014	2.014	35%	65%
Viet Nam	5,161,750	5,161,750	0	200,000	0.056	0.054	100%	0%
Totals	6,733,483,789	2,564,241,265	4,353,952,392	6,938,405	1.072		38%	62%

### Reported Use of Factor Concentrates in 2012: 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 2012 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	14,609,400	14,609,400	0	0	0.391	0.391	100%	0%
Argentina	14,877,300	12,260,000	2,600,000	17,300	0.353	0.352	82%	17%
Australia	26,556,250	3,224,500	23,331,750		1.206		12%	88%
Bangladesh	148,700	0	148,700	148,700	0.001	0.000	0%	100%
Belize	185,000	20,000	165,000	185,000	0.565	0.000	11%	89%
Canada	45,799,681	6,170,922	39,628,759	0	1.335	1.335	13%	87%
Colombia	19,239,000	12,668,800	6,570,200	9,030	0.425	0.425	66%	34%
Cote d'Ivoire	40,000	0	40,000	40,000	0.002	0.000	0%	100%
Cuba	297,500	297,500	0	0	0.027	0.027	100%	0%
Czech Rep.	5,369,862	4,615,700	754,162	0	0.528	0.528	86%	14%
Ecuador	103,200		0	0	0.007	0.007		
Egypt	600,000	100,000	500,000		0.007		17%	83%
Ethiopia	150,000	50,000	100,000	150,000	0.002	0.000	33%	67%
Finland	6,918,500	906,000	6,012,500		1.315		13%	87%
France	57,911,500	29,437,500	28,474,000		0.882		51%	49%
Georgia	4,100,000	4,100,000			0.088		100%	0%
Germany	82,000,000	50,020,000	31,980,000	0	1.009	1.009	61%	39%
Ghana	10,000		10,000	10,000	0.000	0.000	0%	100%
Greece	3,820,406	358,707	3,461,699	0	0.355	0.355	9%	91%
Guatemala	800,000	3,500,000			0.057		438%	0%
Honduras	641,588			641,588	0.077	0.000		
India	5,050,000	5,050,000	0	800,000	0.004	0.004	100%	0%
Iraq	6,000,000		6,000,000	0	0.193	0.193	0%	100%
Ireland	11,850,750	0	11,850,750	0	2.510	2.510	0%	100%
Italy	52,168,700	11,841,200	40,327,500	0	0.852	0.852	23%	77%
Japan	99,300,000	46,600,000	52,700,000	0	0.780	0.780	47%	53%
Jordan	4,556,221				0.700			
Korea, Rep.	37,972,000				0.777			
Kyrgyzstan	16,000				0.003			
Latvia	357,700	357,700	0	0	0.163	0.163	100%	0%
Lebanon	872,350	843,000		29,350	0.211	0.204	97%	0%
Lesotho	3,000	0	0	0	0.002	0.002		
Lithuania	2,154,700	2,154,700	0		0.611		100%	0%

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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
Malaysia	10,364,000	10,364,000	0		0.355		100%	0%
Mauritius	24,000	24,000	0	1,250,000	0.018	0.000	100%	0%
Mexico	17,784,500	17,740,800	43,700	43,700	0.155	0.154	100%	0%
Moldova	594,760	594,760	0	594,760	0.163	0.000	100%	0%
Nepal	486,200			486,200	0.016	0.000		
New Zealand	3,515,500	1,581,000	1,934,500	0	0.812	0.812	45%	55%
Nicaragua	230,000	230,000	0	230,000	0.040	0.000	100%	0%
Nigeria	180,000	0	180,000	180,000	0.001	0.000	0%	100%
Norway	2,180,000	1,990,000	190,000	0	0.463	0.463	91%	9%
Oman	40,000		40,000	0	0.013	0.013	0%	100%
Pakistan	427,000	191,000	236,000	427,000	0.002	0.000	45%	55%
Panama	352,300	352,300	0	0	0.100	0.100	100%	0%
Poland	20,855,800	20,558,300	297,500	0	0.543	0.543	99%	1%
Portugal	5,587,250	4,318,000	1,269,250		0.518		77%	23%
Russia	62,984,840	62,984,840	0	0	0.442	0.442	100%	0%
Saudi Arabia	2,393,500	2,393,500	0	0	0.090	0.090	100%	0%
Senegal	75,000	0	75,000	75,000	0.006	0.000	0%	100%
Serbia	1,375,000	1,375,000	0	0	0.189	0.189	100%	0%
Slovak Rep.	2,200,000	2,200,000	0	0	0.401	0.401	100%	0%
Slovenia	716,500	716,500			0.359		100%	0%
South Africa	6,897,500	6,897,500	0	0	0.141	0.141	100%	0%
Sudan	217,300	217,300			0.006		100%	0%
Sweden	16,314,000	7,129,000	9,185,000	0	1.792	1.792	44%	56%
Switzerland	5,231,000	4,380,000	851,000	0	0.660	0.660	84%	16%
Syria	1,200,000	1,200,000	0	459,000	0.053	0.033	100%	0%
Tunisia	1,233,000	1,233,000	0		0.115		100%	0%
Uganda	57,184	0	57,184		0.002		0%	100%
United Kingdom	82,034,926	9,355,720	72,679,206	0	1.301	1.301	11%	89%
United States	250,100,000	100,000	247,000,000		0.797		0%	99%
Uzbekistan	316,000	316,000			0.011		100%	0%
Venezuela	4,700,000	4,700,000	0	0	0.168	0.168	100%	0%
Viet Nam	212,000	212,000	0	1,580,000	0.002	0.000	100%	0%
<b>Totals</b>	<b>1,005,358,368</b>	<b>372,540,149</b>	<b>588,693,360</b>	<b>7,356,628</b>	<b>0.168</b>		<b>41%</b>	<b>59%</b>

**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 <b>hemophilia A and B</b> (PWH)		<input type="checkbox"/>
2. Number of identified people with <b>von Willebrand disease</b> (vWD)		<input type="checkbox"/>
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		<input type="checkbox"/>
Do you consider these numbers to be accurate?	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>

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



	<input type="checkbox"/> Other (please describe):
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**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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you consider these numbers to be accurate?	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>
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**6.Type of hereditary bleeding disorder**

Diagnosis	Total	Male	Female	Gender unknown	No data
Hemophilia A					<input type="checkbox"/>
Hemophilia B					<input type="checkbox"/>
Hemophilia, type unknown					<input type="checkbox"/>
von Willebrand disease					<input type="checkbox"/>
Factor I deficiency					<input type="checkbox"/>
Factor II deficiency					<input type="checkbox"/>
Factor V deficiency					<input type="checkbox"/>
Factor V+VIII deficiency					<input type="checkbox"/>
Factor VII deficiency					<input type="checkbox"/>
Factor X deficiency					<input type="checkbox"/>
Factor XI deficiency					<input type="checkbox"/>
Factor XIII deficiency					<input type="checkbox"/>
Other hereditary bleeding disorders: type unknown					<input type="checkbox"/>
Platelet disorders: Glanzmann's thrombasthenia					<input type="checkbox"/>
Platelet disorders: Bernard Soulier Syndrome					<input type="checkbox"/>
Platelet disorders: other or unknown					<input type="checkbox"/>

Do you consider these numbers to be accurate?	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>
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**7. How are patients with rare bleeding disorders (deficiency in FI, FII, FV, FV+VIII, FVII, FX, FXI FXIII) identified?**

Factor level below 5% <input type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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**How are patients with von Willebrand Disease identified?**

Laboratory diagnosis <input type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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**8. Number of identified people with hemophilia by 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					<input type="checkbox"/>
Hemophilia A female					<input type="checkbox"/>
Hemophilia B male					<input type="checkbox"/>
Hemophilia B female					<input type="checkbox"/>

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

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

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

Type of hemophilia	Number with current inhibitors	No Data
Hemophilia A		<input type="checkbox"/>
Hemophilia B		<input type="checkbox"/>

**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			<input type="checkbox"/>
Hepatitis C			<input type="checkbox"/>

**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			<input type="checkbox"/>
Hepatitis C			<input type="checkbox"/>

**15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2012)**

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.

<b>16.</b> How many <b>hemophilia treatment centres</b> are there in your country?	
How many <b>hemophilia comprehensive care centres</b> 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.

<b>17.</b> What percentage of children (under age 18) are on prophylaxis?		Precise: <input type="checkbox"/>	Not known <input type="checkbox"/>
		Estimate: <input type="checkbox"/>	
What percentage of adults (over age 18) are on prophylaxis?		Precise: <input type="checkbox"/>	Not known <input type="checkbox"/>
		Estimate: <input type="checkbox"/>	

### 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 2012?			<input type="checkbox"/>
How many international units of <b>plasma-derived</b> concentrates were used in your country in 2012?			<input type="checkbox"/>
How many international units of <b>recombinant</b> concentrates were used in your country in 2012?			<input type="checkbox"/>
How many international units were <b>humanitarian aid</b> ?			<input type="checkbox"/>



## 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.







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