WORLD FEDERATION OF HEMOPHILIA

REPORT ON THE

ANNUAL GLOBAL SURVEY 2016

WFH

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

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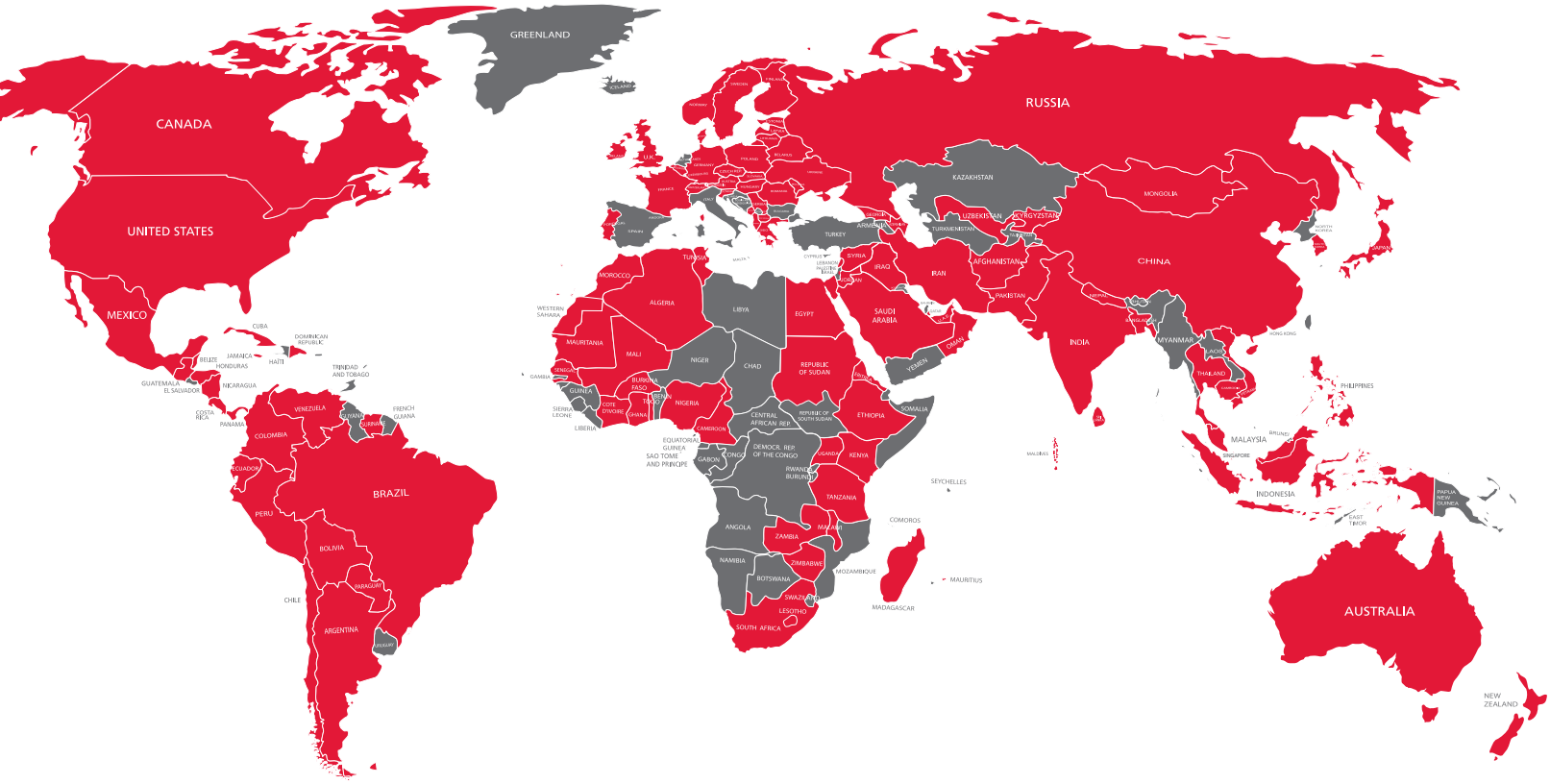
COUNTRIES INCLUDED IN THE REPORT ON THE ANNUAL GLOBAL SURVEY 2016



Countries included

Countries not included

The WFH has a total of 134 National Member Organizations (NMOs). The Report on the Annual Global Survey 2016 includes data from 113 NMOs.

INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2016

The Report on the Annual Global Survey 2016 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. The purpose of this report is to provide hemophilia organizations, hemophilia treatment centres (HTCs), and health officials with useful information to support efforts to improve or sustain the care of people with bleeding disorders and to assist with program planning. Supplementary charts and graphs using 2016 data can be found on the website at: **www.wfh.org/en/data-collection**.

Methodology

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

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization. The 2016 survey is the eighteenth WFH survey. This report also uses data from the year 2015. Not all of our members are able to report every year. Previous Annual Global Survey reports have used historical data going back more than 1 year. A list of participating countries and the last year they provided data can be found on page 27 . This report includes data on more than 295,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 113 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.

Total population numbers are used in Table 6 Population statistics and in the calculation for factor VIII and IX per capita (Table 16 and 17). The source from 1999 to 2014 was The World Factbook, Central Intelligence Agency. As of 2015, this was changed to The World Bank Group. General population numbers are estimates based on national government data.

Comments on the graphs

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

Comments on data collection

Participation in the Annual Global Survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. Some countries are only able to provide detailed data on gender, age, inhibitors and HIV/HCV infection for a limited subset of patients. For example, they may know the total number of people with hemophilia in the country but only have age and gender data from a single treatment centre. This report provides information on the annual usage of treatment products for 2016 only. It includes only those countries where the national hemophilia organization provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2016. In some cases the numbers reported may be based on an estimate or from one region or hospital only. The amounts reported may only be factor bought through government and not through other sources. Not all national hemophilia organizations are able to report on all products used in their country. Although factor use per capita is a useful way to compare the availability of treatment products between countries, it is not a reflection of how individual patients are treated. For example, in a country with a lower than expected number of identified patients, the amount of treatment product available per patient is higher than the per capita number would suggest.

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

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

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

c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they do not 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 can be time consuming and expensive. It is possible that some registries contain patients who have been double-entered or have died. Even wealthy countries with excellent registries have to carefully review their records to avoid over-counting. Countries with large populations are more susceptible to over-counting. It is harder to keep track of births and deaths. Some patients may be registered in more than one treatment centre and validation of registry data is more difficult.

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

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

The Report on the Annual Global Survey is collected under the supervision of the WFH Data & Demographics Committee, including:

Chair: Alfonso Iorio

Members: Vanessa Byams
Magdy El Ekiaby
Mike Makris
Jamie O'Hara
Alok Srivastava
Jeff Stonebraker
Marijke van den Berg

Annual Global Survey Reviewers:
Paula Bolton-Maggs
Randall Curtis
Suely Rezende
Mike Soucie

KEY NUMBERS

From the 2016 Report on the Annual Global Survey

72%
Response Rate from WFH National Member Organizations (97/134)

113
Countries Represented

295,866
People with bleeding disorders identified

184,723
People with Hemophilia

149,764
People with Hemophilia A

29,712
People with Hemophilia B

Factor VIII Usage per capita
0.83 IU
(0.07 – 4.18)
Median (IQR)
(91 countries, 69% of world population)

39,495
People with Other Bleeding Disorders

71,648
People with von Willebrand disease (VWD)

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REPORT ON THE ANNUAL GLOBAL SURVEY **2016** **SUMMARY DEMOGRAPHICS**

Table 1. Demographics

Number of countries in this survey	**113**
Percentage of world population covered by countries included in 2016 survey report	**90%**
Number of people identified with hemophilia	**184,723**
Number of people identified with von Willebrand disease	**71,648**
Number of people identified with other bleeding disorders	**39,495**
Total number of people identified with bleeding disorders	**295,866**
Number of people identified with hemophilia A	**149,764**
Number of people identified with hemophilia B	**29,712**
Number of people with hemophilia A with current clinically identified inhibitors	**4,711**
Number of people with hemophilia B with current clinically identified inhibitors	**280**

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

PLEASE NOTE: The Report on the Annual Global Survey 2016 also uses data from the year 2015. For the 2016 survey report, 97 countries submitted data for 2016. Historical data from 2015 was used for 16 countries. 2015 surveys are only used for reporting the number of patients identified (Tables 1, 6, 7 and 8). Reducing the amount of historical data is part of our effort to improve the overall quality of data we report each year.

Table 2. Factor VIII usage 2016

	FACTOR USAGE	NUMBER OF COUNTRIES
Mean global per capita factor VIII usage	**2.29 IU**	**91**
Median global per capita factor VIII usage	**0.83 IU**	**91**
Interquartile range (IQR) global per capita factor VIII usage	**4.12 IU (0.07 to 4.18)**	**91**
Total reported annual global consumption of factor VIII concentrates	**9,986,083,762 IU**	**91**

Table 3. Factor IX usage 2016

	FACTOR USAGE	NUMBER OF COUNTRIES
Mean global per capita factor IX usage	**0.38 IU**	**87**
Median global per capita factor IX usage	**0.17 IU**	**87**
Interquartile range (IQR) global per capita factor IX usage	**0.62 IU (0.01 to 0.63)**	**87**
Total reported annual global consumption of factor IX concentrates	**1,599,691,148 IU**	**87**

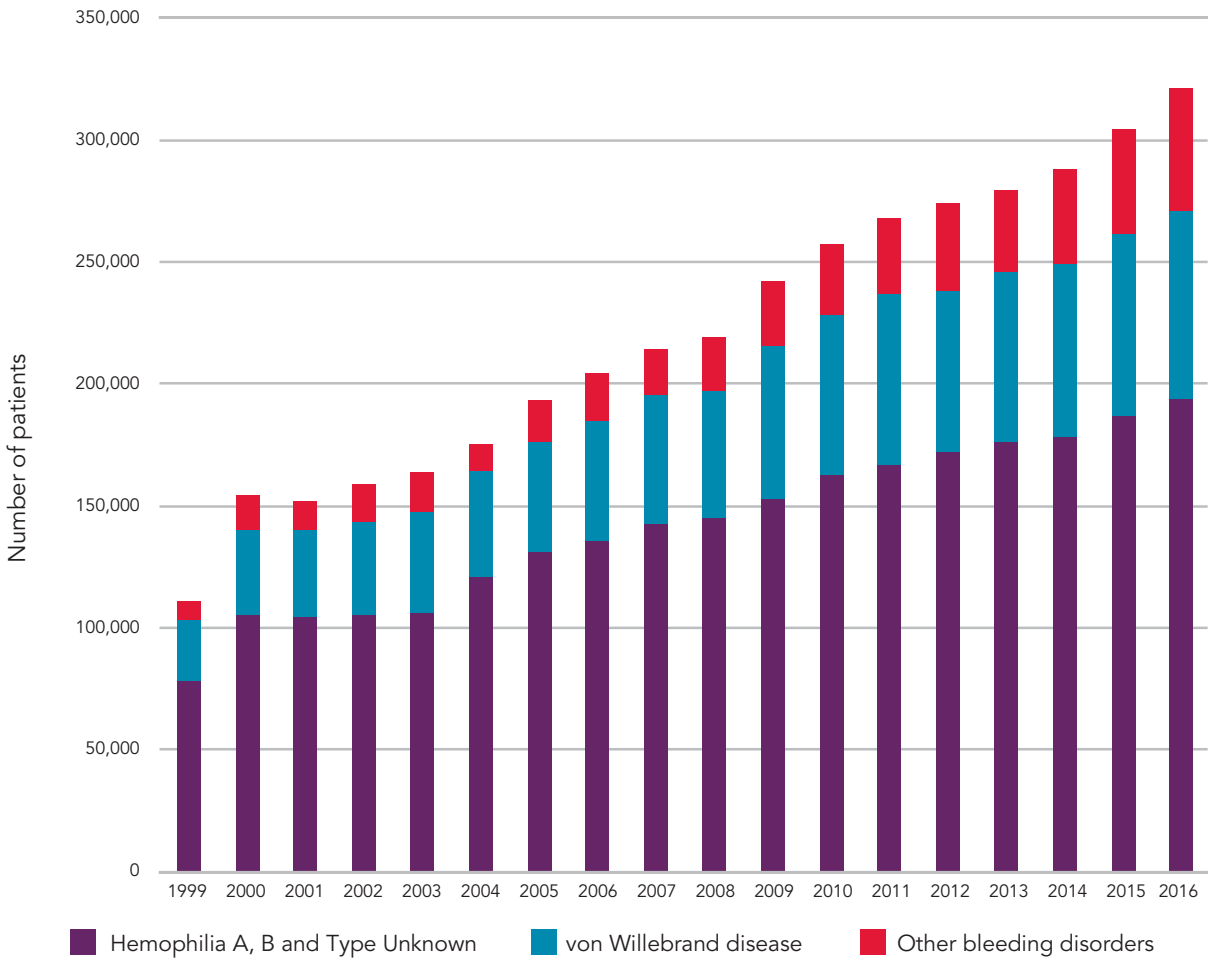
The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using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

The chart below shows average per capita factor use for the countries that reported in both the 2015 and 2016 surveys.

Table 4. Factor use in 2015 and 2016

	2015	2016	COUNTRIES REPORTING
Mean global per capita factor VIII usage	**2.30 IU**	**2.35 IU**	**67**
Median global per capita factor VIII usage	**0.53 IU**	**1.05 IU**	**67**
Interquartile range (IQR) global per capita factor VIII usage	**3.89 IU (0.02 to 3.91)**	**4.28 IU (0.11 to 4.39)**	**67**
Mean global per capita factor IX usage	**0.41 IU**	**0.43 IU**	**59**
Median global per capita factor IX usage	**0.16 IU**	**0.29 IU**	**59**
Interquartile range (IQR) global per capita factor IX usage	**0.66 IU (0.005 to 0.66)**	**0.72 IU (0.01 to 0.74)**	**59**

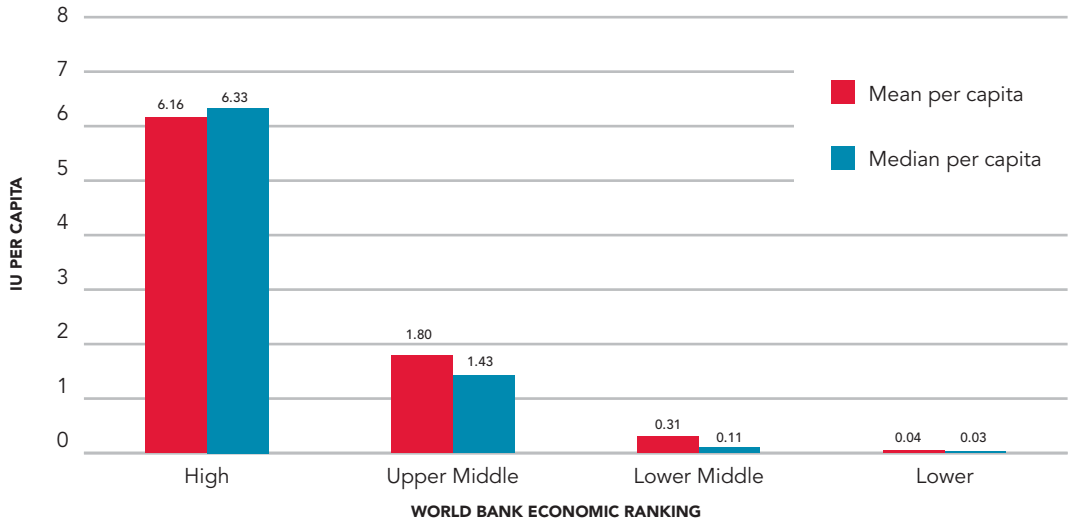
Figure A. Identified patients over time – all bleeding disorders



This graph showing the increase over time in patients identified contains historical data from 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. The Report on the Annual Global Survey 2016 uses 1 year of historical data for the number of patients identified; however, for each year in ***Figure A, historical data for up to 3 years is used.*** *This reflects an estimate of the total number of identified patients with inherited bleeding disorders. Figure A provides a historical snapshot of the growth in patient identification.*

Figure B1. Mean global factor VIII use per capita

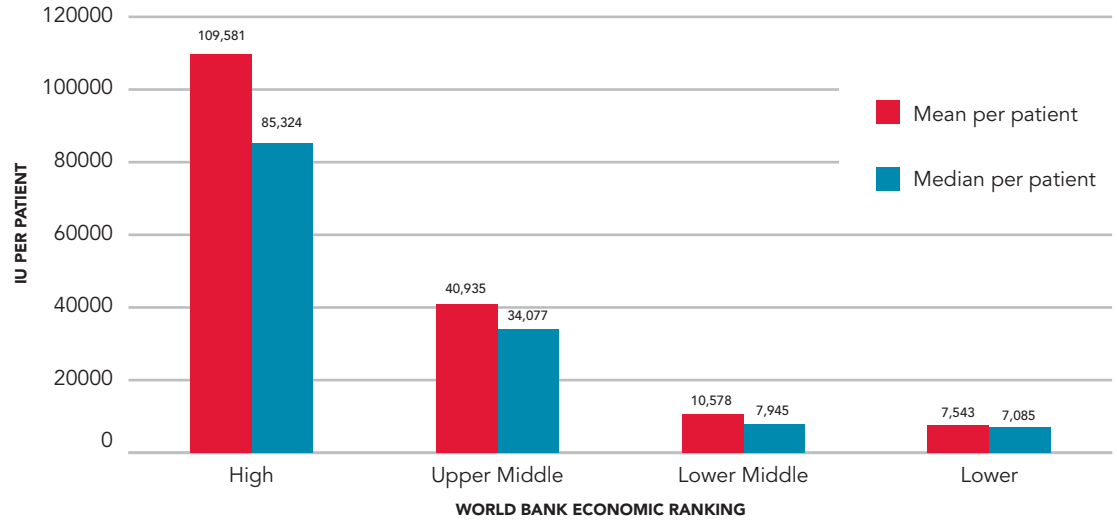
(Data from 79 countries.)



Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.)

Figure B2. Mean global factor VIII use per patient

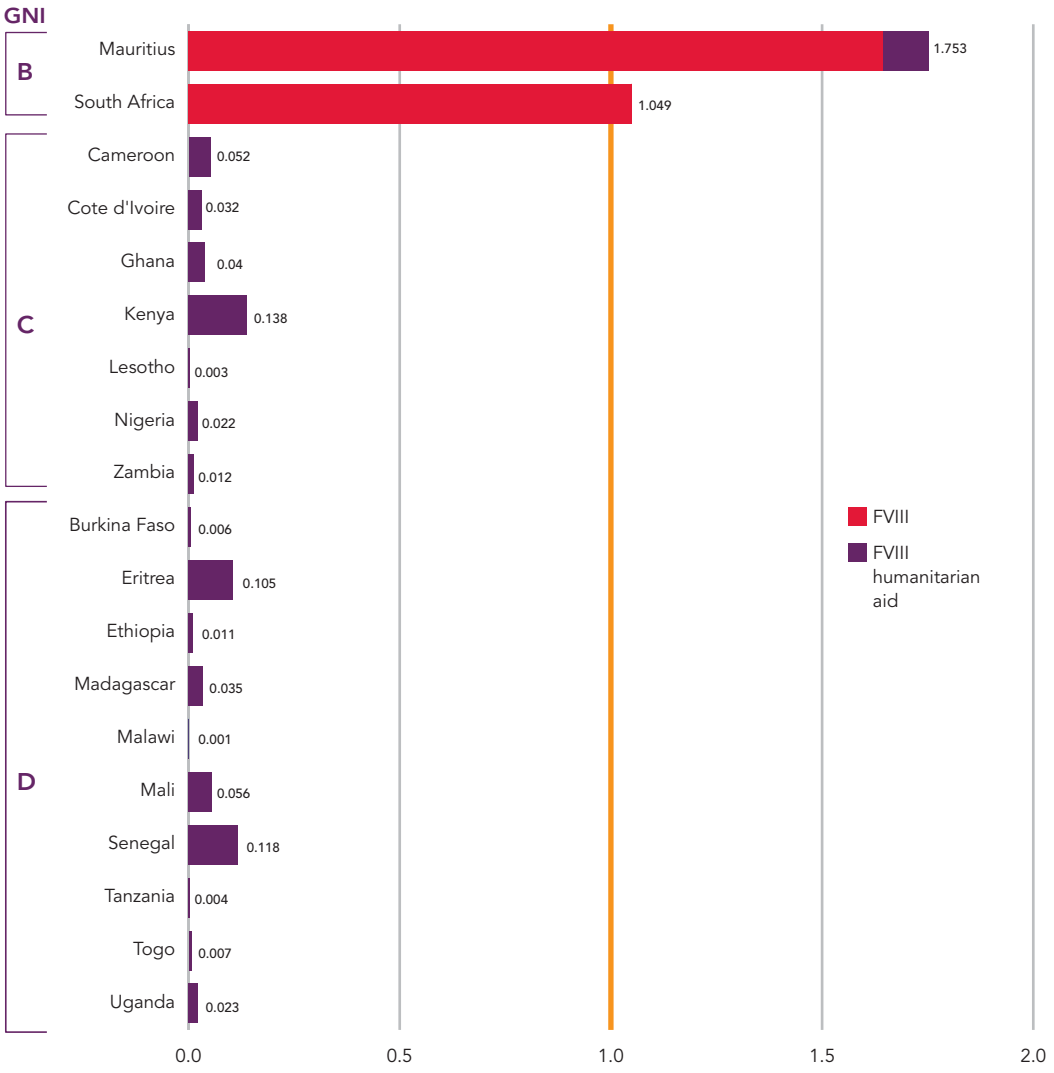
(Data from 79 countries.)



Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.)

Numbers in Figure B2 are calculated based on reported factor VIII use and the number of identified hemophilia A patients. We do not have data on individual treatment. WFH humanitarian aid donations are included.

Figure C1a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Africa



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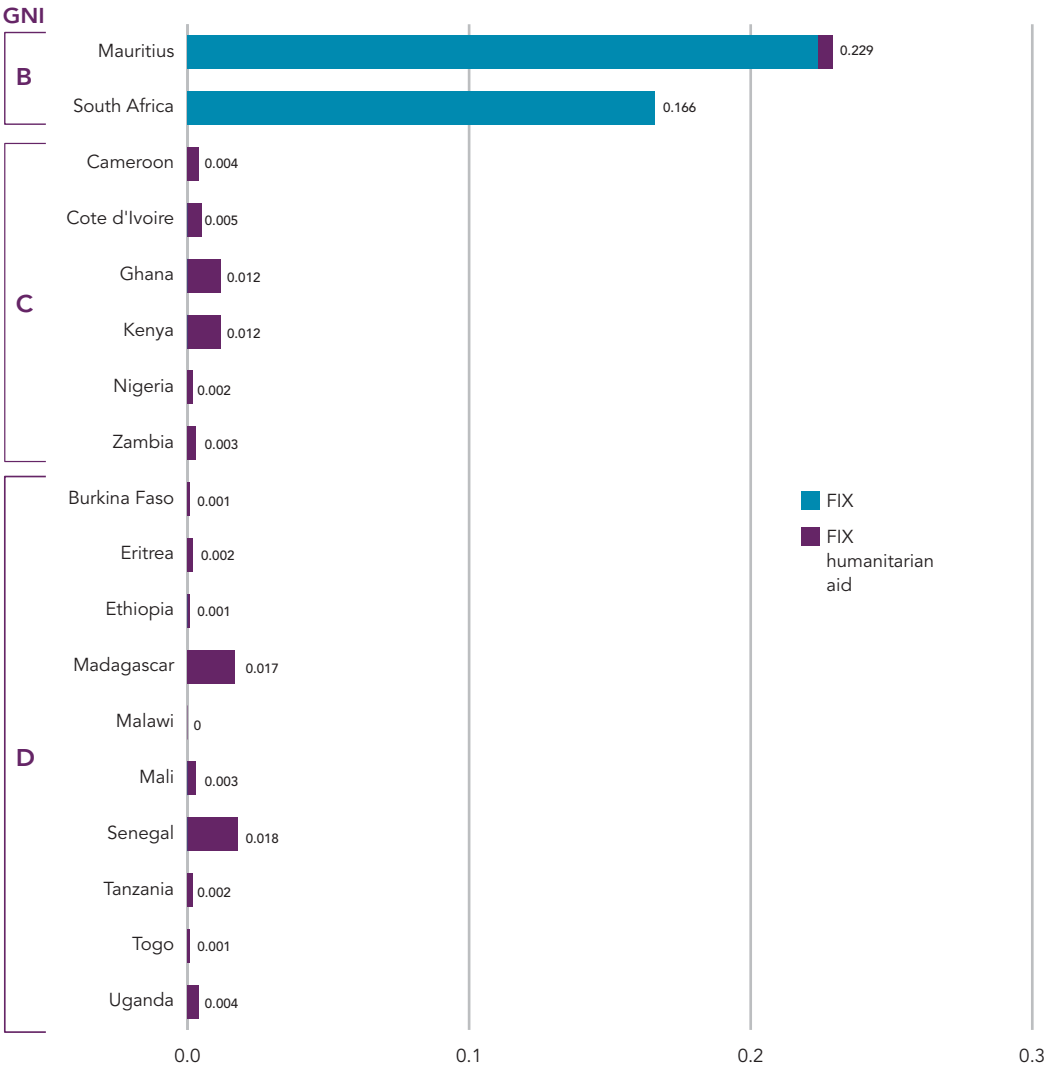
PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve 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. Only countries that completed the 2016 questionnaire are included in these charts.

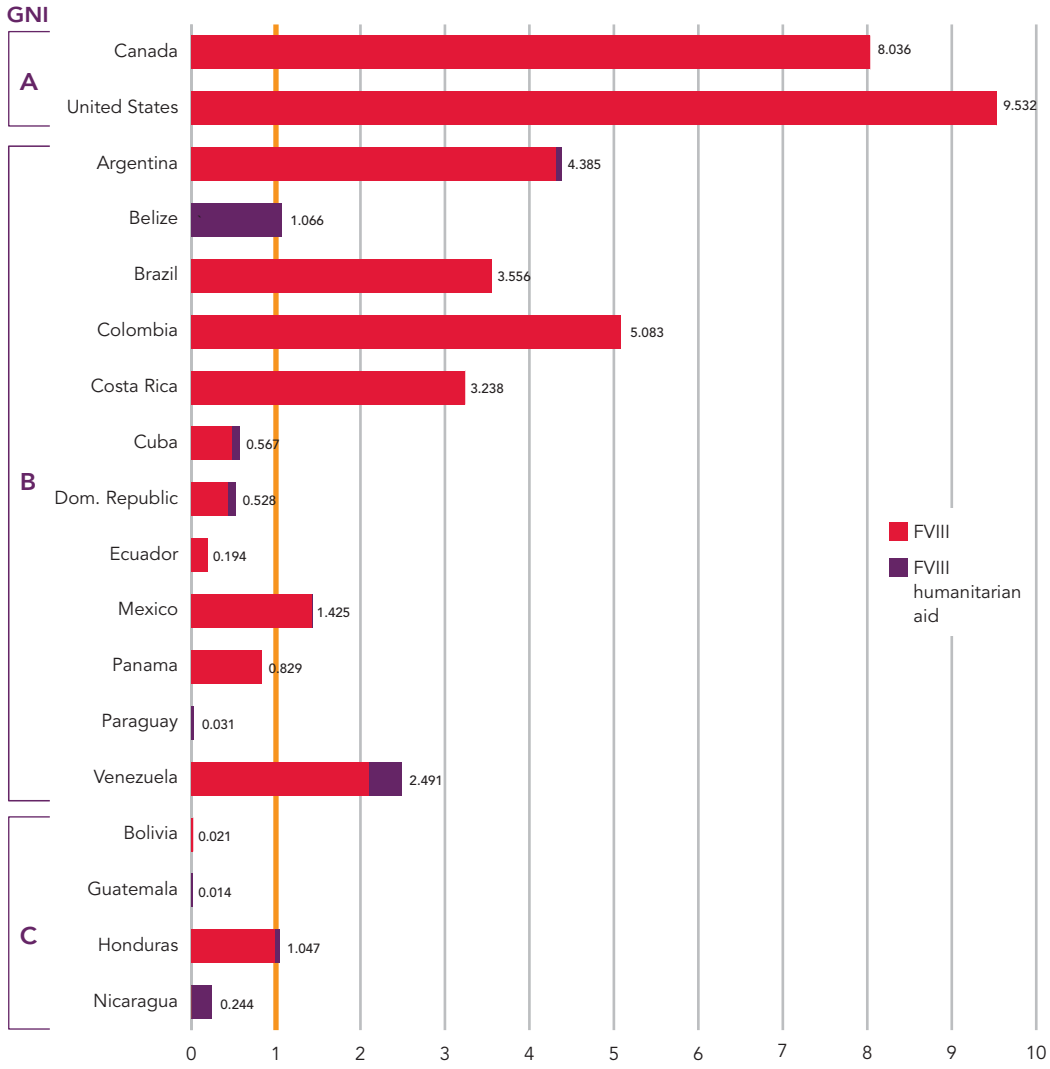
Figure C1b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Africa



Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. Only countries that completed the 2016 questionnaire are included in these charts.

Figure C2a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Americas



Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.) (Regions based on WHO regions.)

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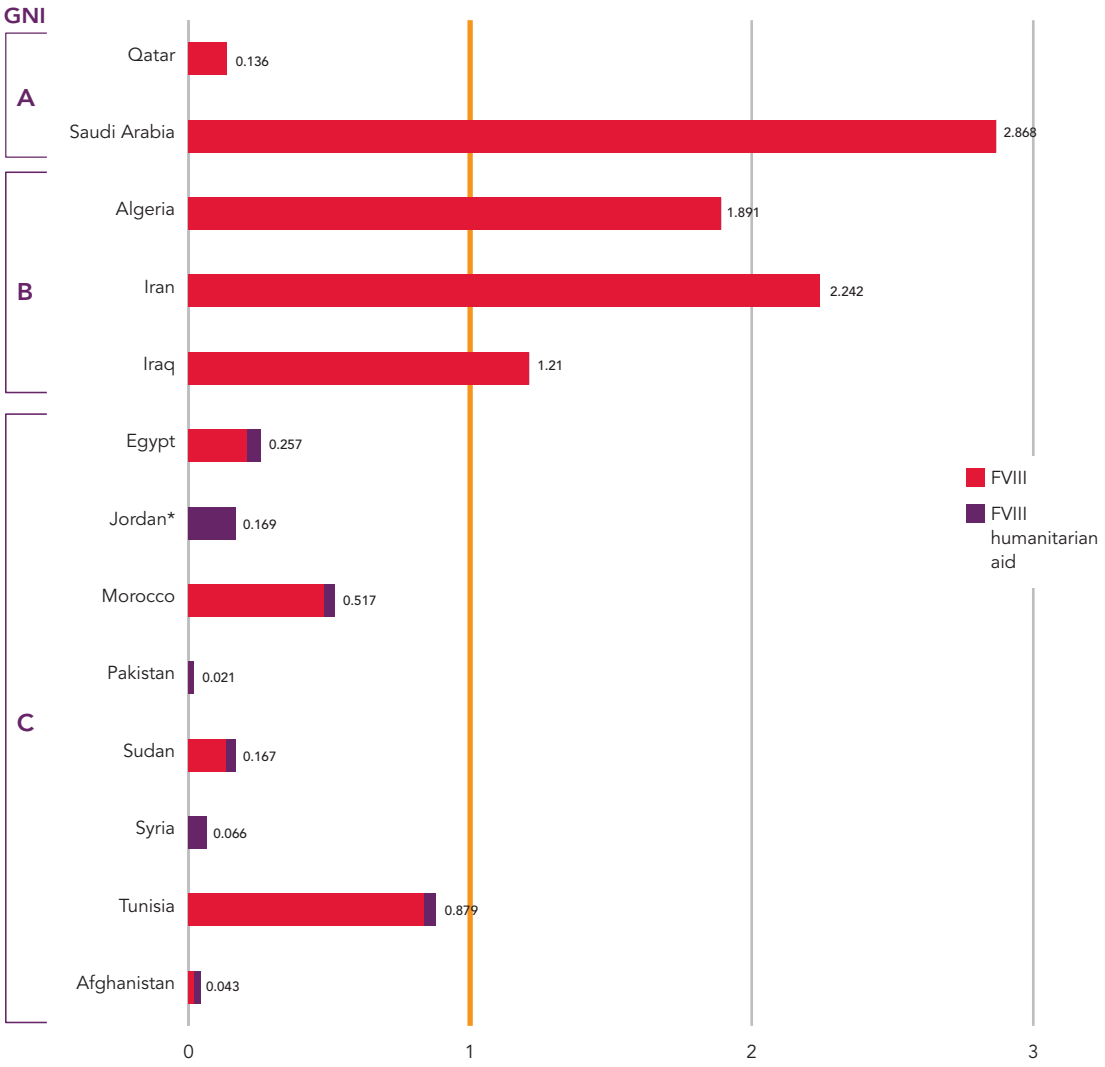
Figure C2b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Americas

Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. Only countries that completed the 2016 questionnaire are included in these charts.

Figure C3a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



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**There are some countries where product is purchased but the quantities are unknown. The per capita number only reflects donations, as verified with WFH data on humanitarian aid. Where we are aware of this situation, we have marked this country with an asterisk.*

Figure C3b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Eastern Mediterranean

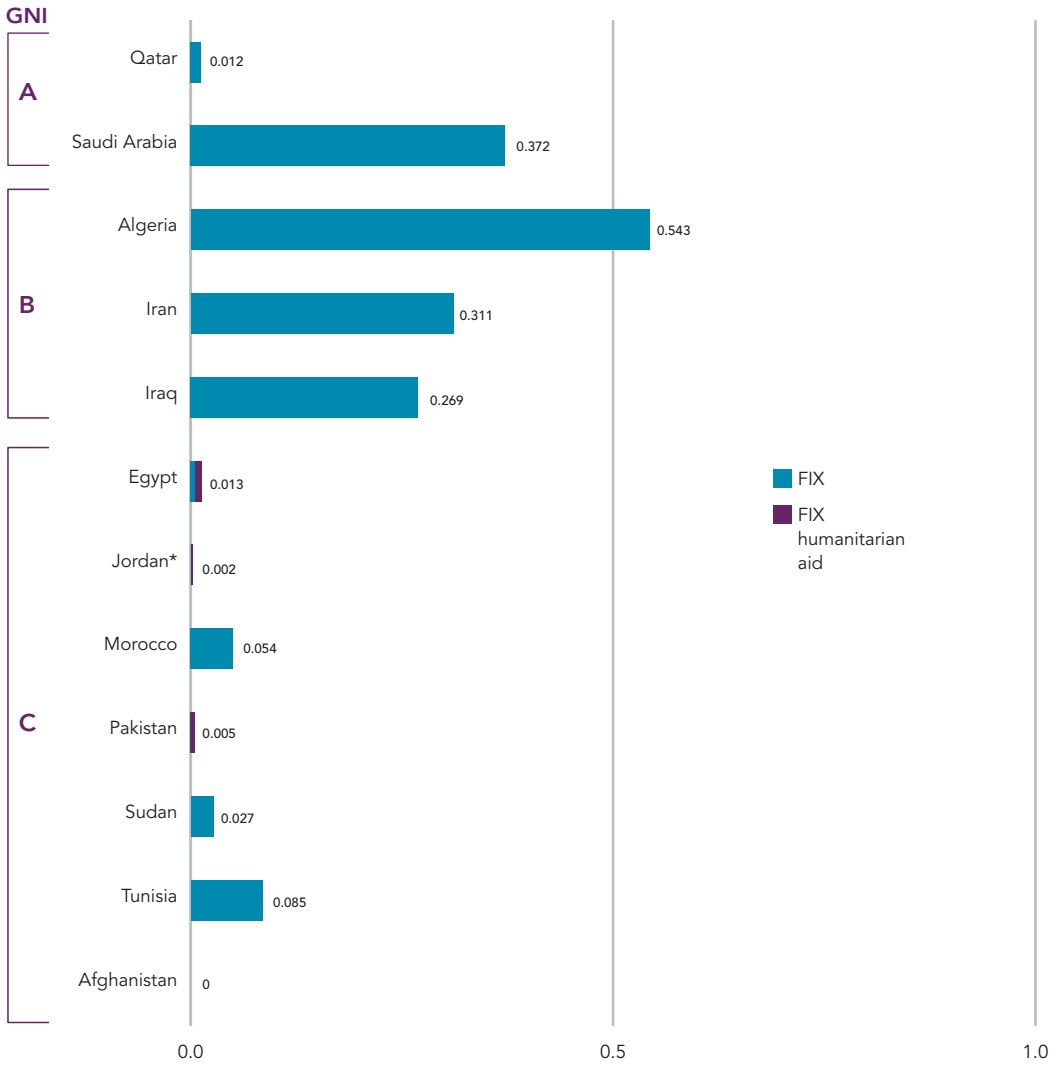

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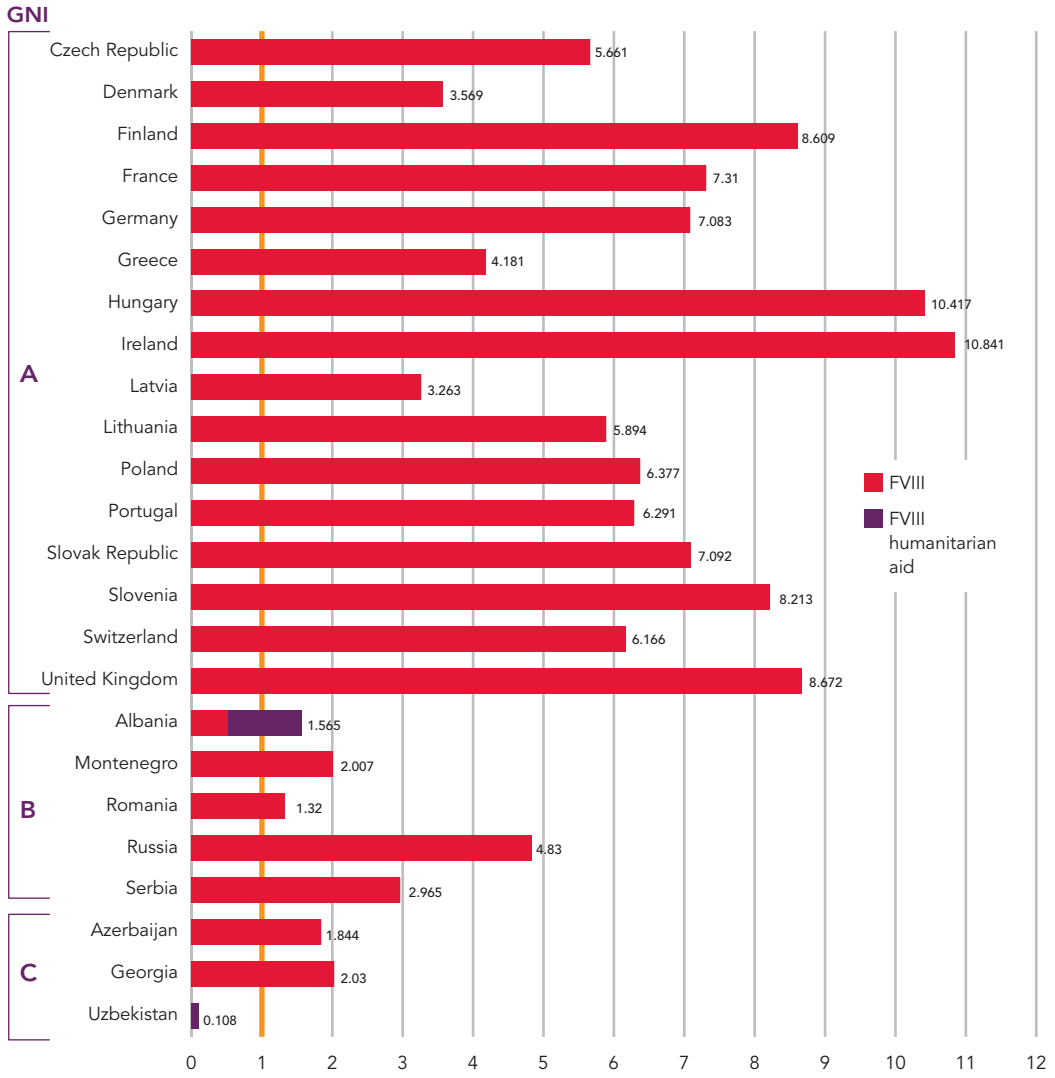
Figure C4a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Europe



Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $12,235 and A high income, $12,235 or more.) (Regions based on WHO regions.)

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Figure C4b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Europe

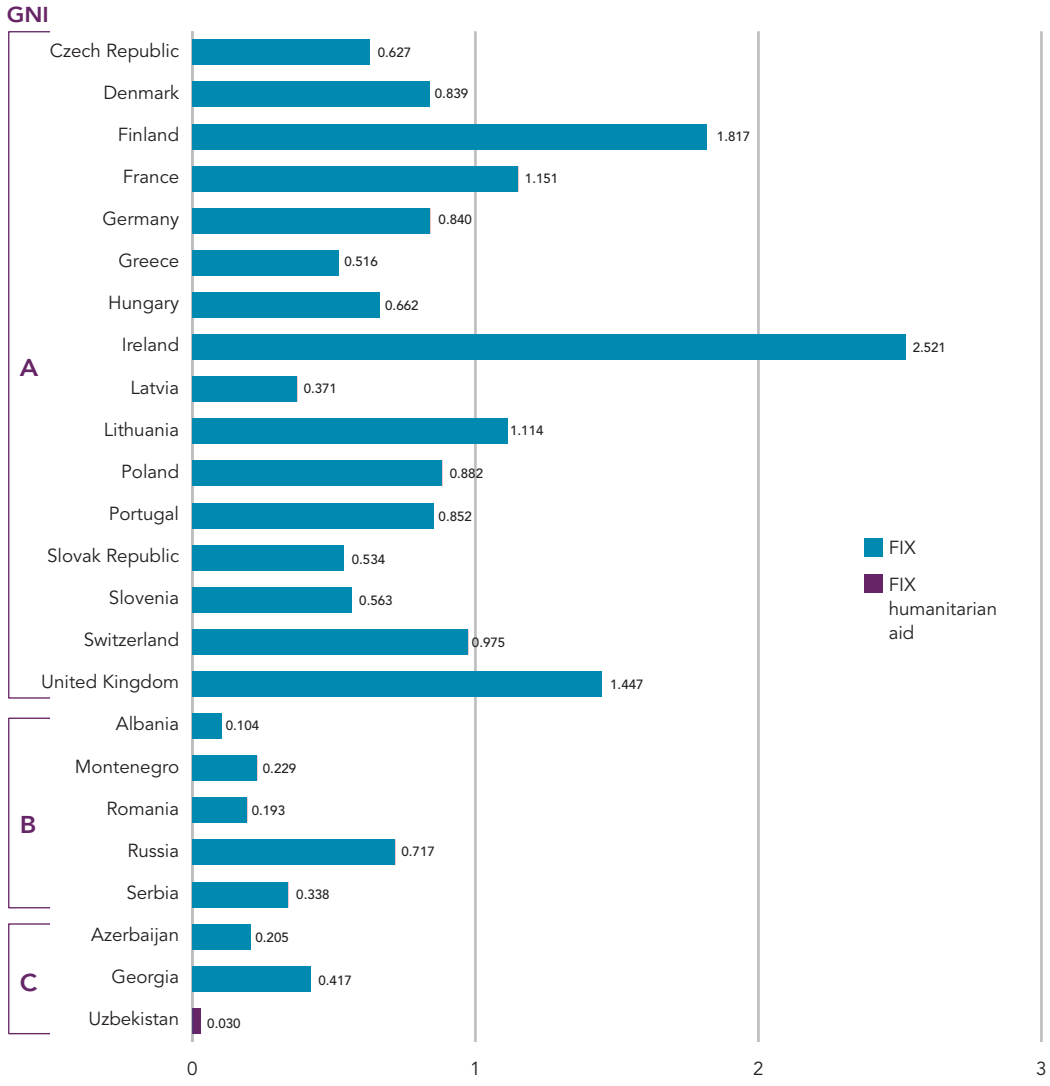

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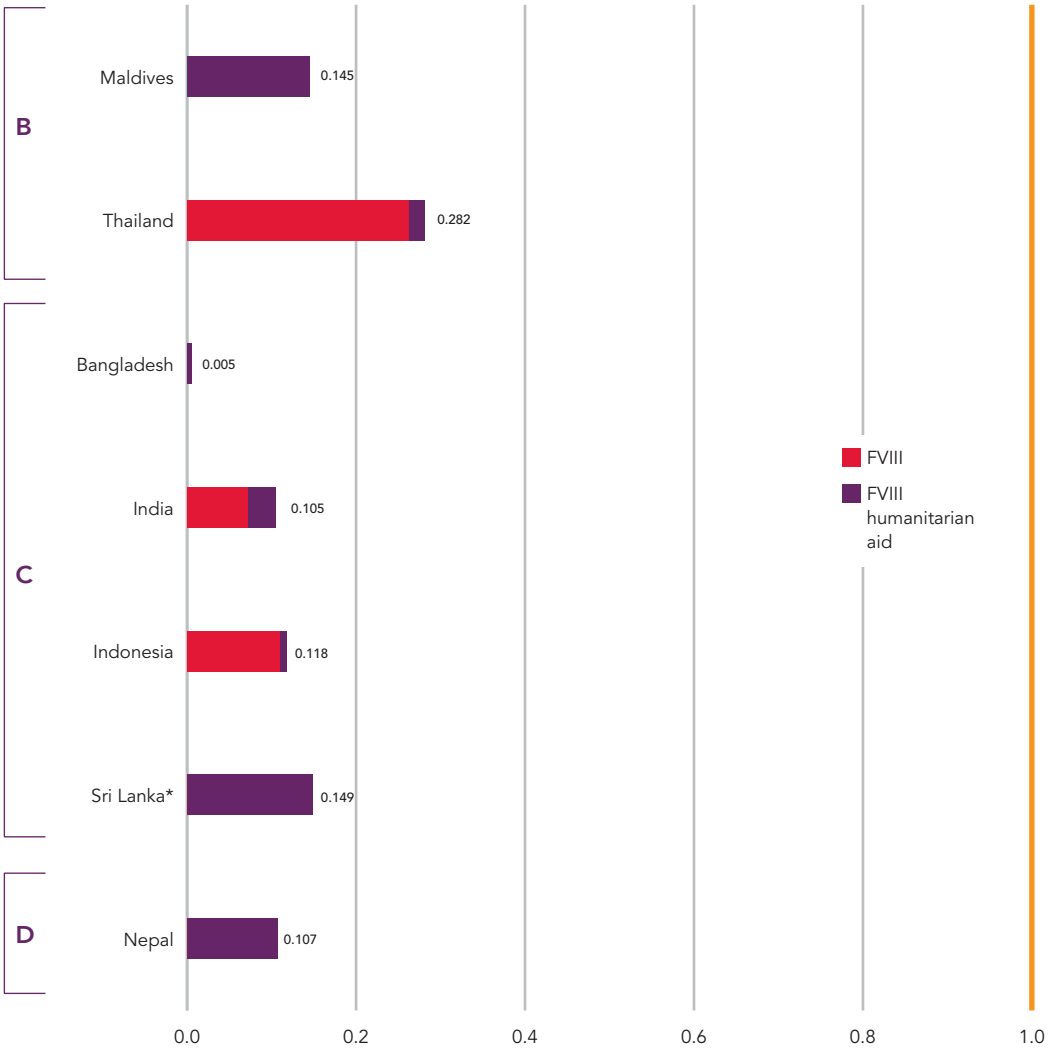
Figure C5a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: South-East Asia



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**There are some countries where product is purchased but the quantities are unknown. The per capita number only reflects donations, as verified with WFH data on humanitarian aid. Where we are aware of this situation, we have marked this country with an asterisk.*

Figure C5b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: South-East Asia

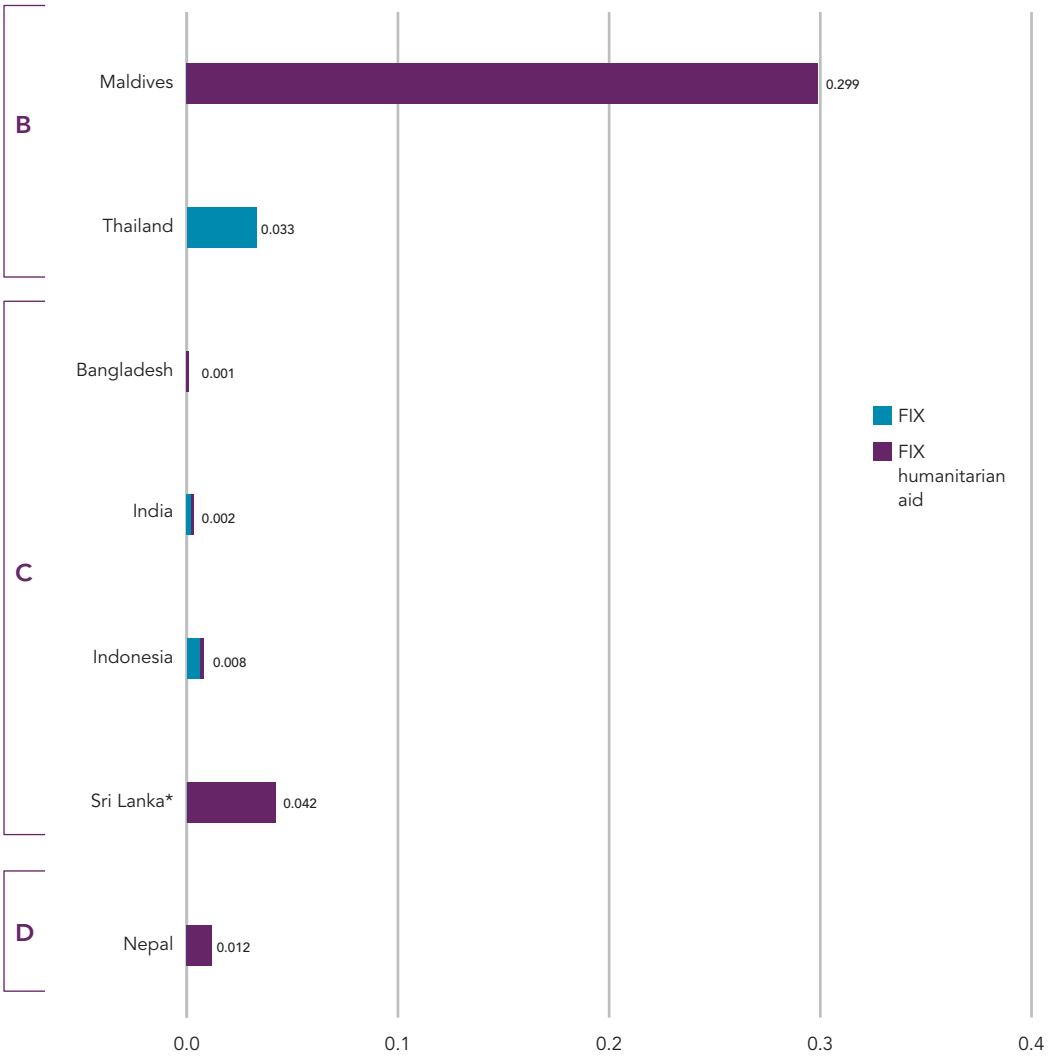

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Figure C6a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Western Pacific

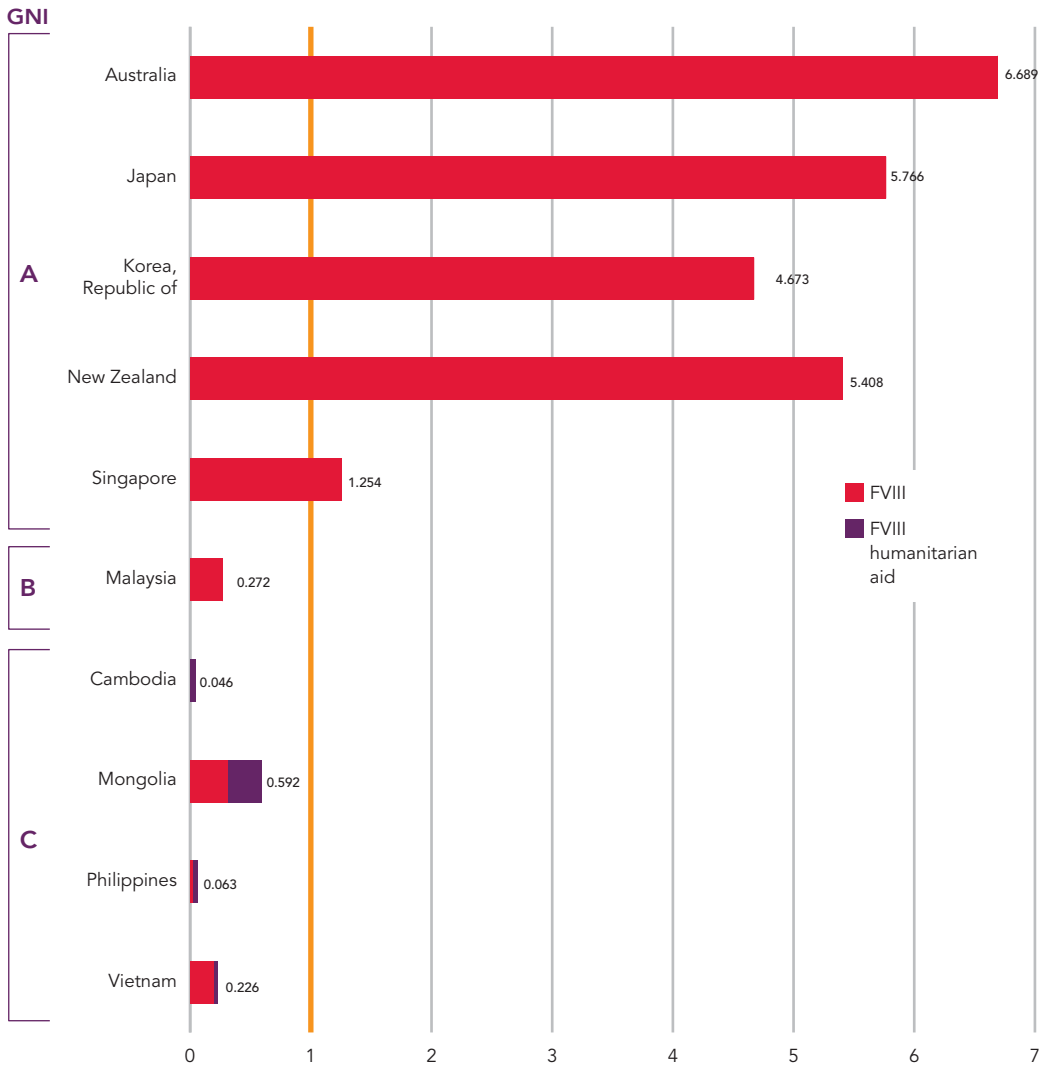

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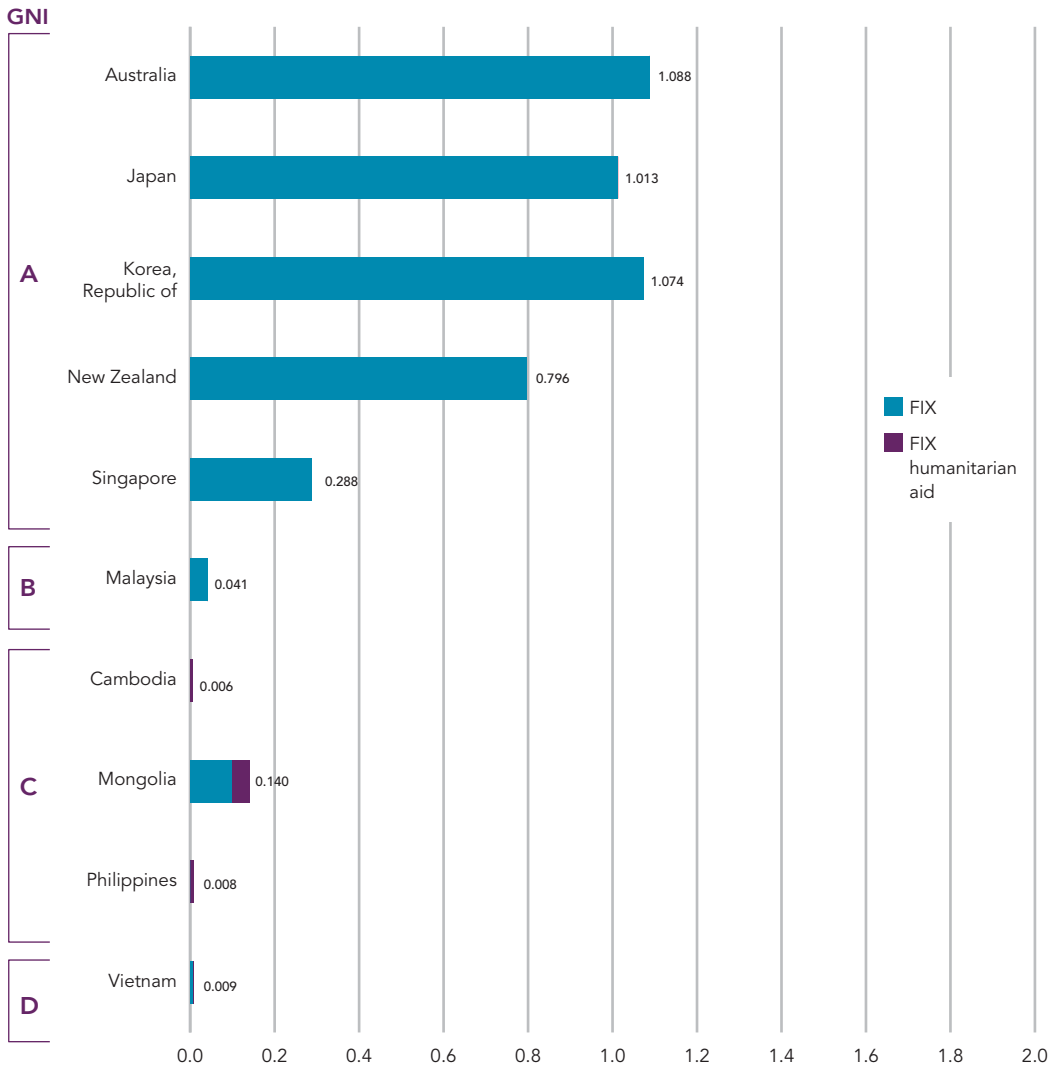
Figure C6b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Western Pacific



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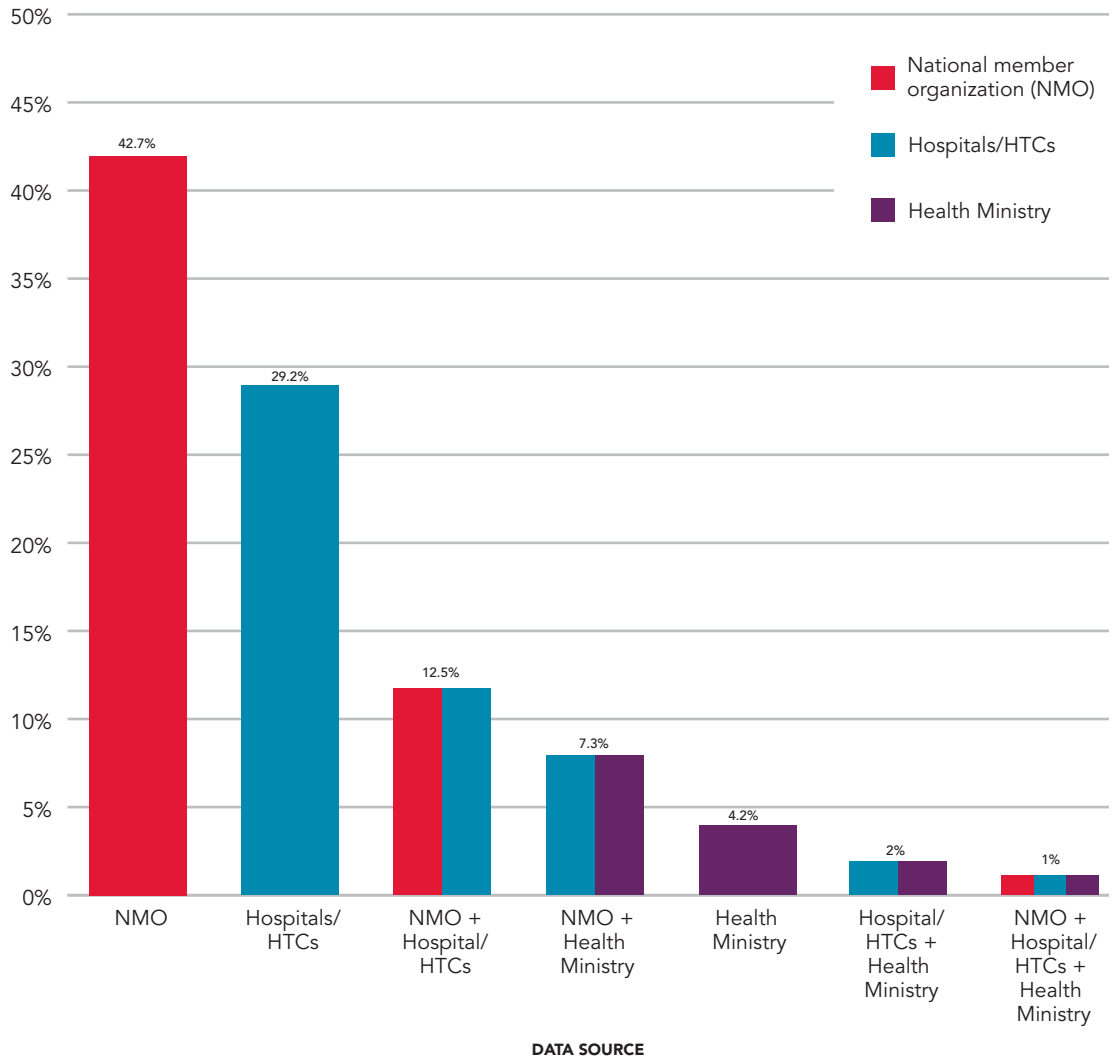
PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. Only countries that completed the 2016 questionnaire are included in these charts.

Figure D. Data source

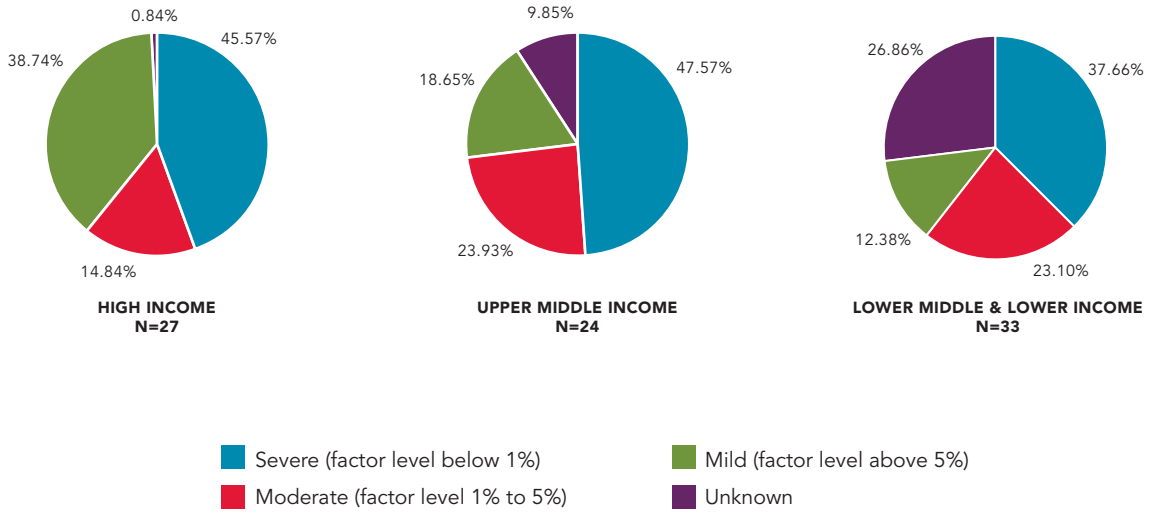


Members were asked the source of the numbers provided for the survey. Possible answers were: Hemophilia Society and/or national member organization (NMO) registry or database, Hospital(s)/HTC(s) registry or database, Health Ministry registry or database or Other. Many members used multiple sources to obtain data.

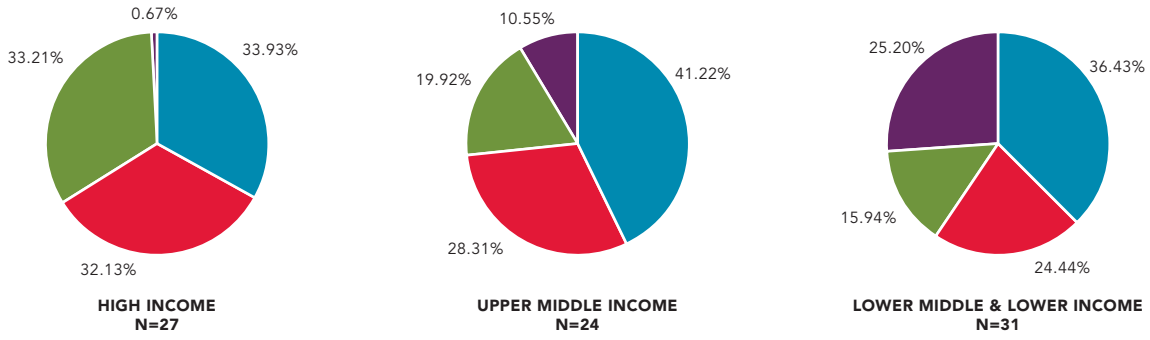
Figure E1. Severity of hemophilia, males

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

Hemophilia A



Hemophilia B

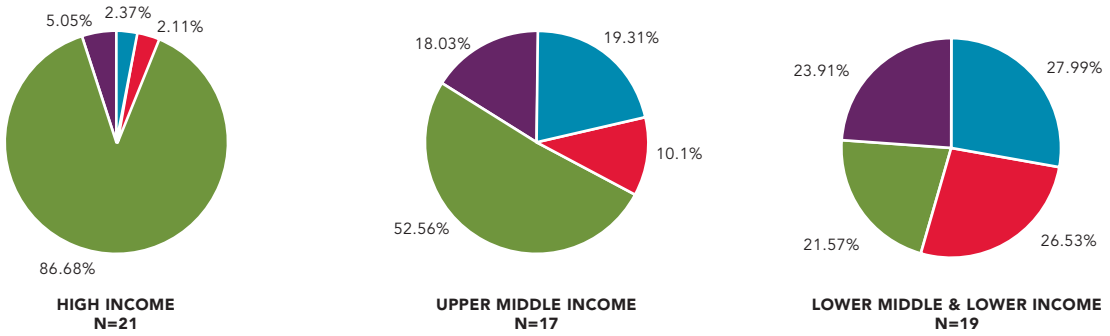


Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.)

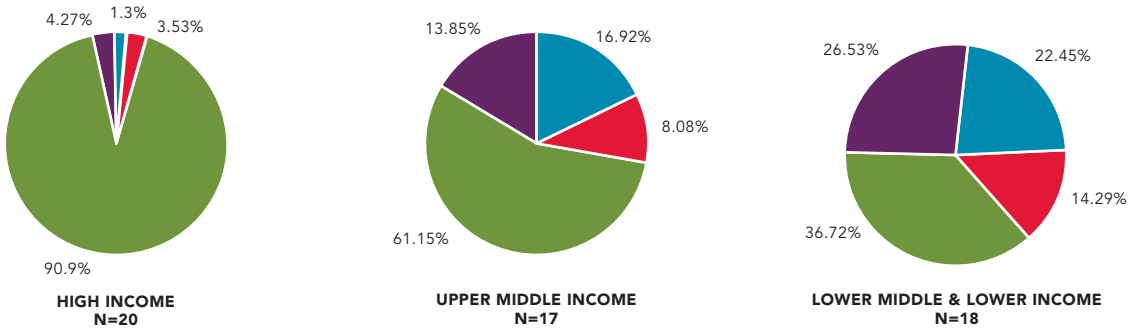
Figure E2. Severity of hemophilia, females

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

Hemophilia A



Hemophilia B



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.)

Table 5. Countries included in the Report on the Annual Global Survey 2016

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 2016 survey report, 97 countries submitted data for 2016. Countries in **BOLD** reported data for 2016.

Data from 2015 was used for 16 countries. 2015 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2016 only.

Afghanistan	2016	**Estonia**	2016	**Malawi**	2016	**Senegal**	2016
Albania	2016	**Ethiopia**	2016	**Malaysia**	2016	**Serbia**	2016
Algeria	2016	**Finland**	2016	**Maldives**	2016	**Singapore**	2016
Argentina	2016	**France**	2016	**Mali**	2016	**Slovak Republic**	2016
Australia	2016	**Georgia**	2016	Mauritania	2015	**Slovenia**	2016
Austria	2016	**Germany**	2016	**Mauritius**	2016	**South Africa**	2016
Azerbaijan	2016	**Ghana**	2016	**Mexico**	2016	**Sri Lanka**	2016
Bangladesh	2016	**Greece**	2016	Moldova	2015	**Sudan**	2016
Belarus	2015	**Guatemala**	2016	**Mongolia**	2016	Suriname	2015
Belgium	2016	**Honduras**	2016	**Montenegro**	2016	Sweden	2015
Belize	2016	Hong Kong (China)	2015	**Morocco**	2016	**Switzerland**	2016
Bolivia	2016	**Hungary**	2016	**Nepal**	2016	**Syria**	2016
Brazil	2016	**India**	2016	**New Zealand**	2016	**Tanzania**	2016
Burkina Faso	2016	**Indonesia**	2016	**Nicaragua**	2016	**Thailand**	2016
Cambodia	2016	**Iran**	2016	**Nigeria**	2016	**Togo**	2016
Cameroon	2016	**Iraq**	2016	**Norway**	2016	**Tunisia**	2016
Canada	2016	**Ireland**	2016	**Oman**	2016	**Uganda**	2016
Chile	2015	Jamaica	2015	**Pakistan**	2016	Ukraine	2015
China	2016	**Japan**	2016	Palestine	2015	United Arab Emirates	2015
Colombia	2016	**Jordan**	2016	**Panama**	2016	**United Kingdom**	2016
Costa Rica	2016	**Kenya**	2016	**Paraguay**	2016	**United States**	2016
Cote d'Ivoire	2016	**Korea, Republic of**	2016	Peru	2015	**Uzbekistan**	2016
Cuba	2016	Kyrgyzstan	2015	**Philippines**	2016	**Venezuela**	2016
Czech Republic	2016	**Latvia**	2016	**Poland**	2016	**Vietnam**	2016
Denmark	2016	Lebanon	2015	**Portugal**	2016	**Zambia**	2016
Dominican Republic	2016	**Lesotho**	2016	**Qatar**	2016	Zimbabwe	2015
Ecuador	2016	**Lithuania**	2016	**Romania**	2016		
Egypt	2016	Macedonia	2015	**Russia**	2016		
Eritrea	2016	**Madagascar**	2016	**Saudi Arabia**	2016		

Table 6. Population statistics

Please note: in all of the population charts a 0 indicates that the member organization reported the number zero and "Not known" means that the member organization reported that they do not know the answer. Countries in **BOLD** reported data for 2016. For countries that did not report population statistics for 2016 but did report during the year 2015, we used the most recent number of patients reported. 2015 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2016 only.

The source of population data from 1999 to 2014 was The World Factbook, Central Intelligence Agency. As of 2015, population data is sourced from The World Bank Group.

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Afghanistan	34,656,032	306	Not Known	Not Known
Albania	2,876,101	189	4	6
Algeria	40,606,052	2,160	298	536
Argentina	43,847,430	2,630	401	10
Australia	24,127,159	2,576	2,092	722
Austria	8,747,358	772	Not Known	Not Known
Azerbaijan	9,762,274	1,334	207	113
Bangladesh	162,951,560	900	2	3
Belarus	9,513,000	564	192	48
Belgium	11,348,159	1,212	1,906	455
Belize	366,954	16	Not Known	Not Known
Bolivia	10,887,882	200	1	Not Known
Brazil	207,652,865	12,119	7,811	2,872
Burkina Faso	18,646,433	46	Not Known	Not Known
Cambodia	15,762,370	153	4	6
Cameroon	23,439,189	176	2	0
Canada	36,286,425	3,893	4,437	1,932
Chile	17,948,141	1,547	483	473
China	1,378,665,000	14,390	72	90
Colombia	48,653,419	2,059	1,471	282
Costa Rica	4,857,274	210	71	36
Cote d'Ivoire	23,695,919	81	3	3
Cuba	11,475,982	470	351	3,220
Czech Republic	10,561,633	1,076	818	109

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Denmark	5,731,118	523	309	145
Dominican Republic	10,648,791	370	17	16
Ecuador	16,385,068	132	48	3
Egypt	95,688,681	5,549	543	1,205
Eritrea	5,869,869	54	Not Known	Not Known
Estonia	1,316,481	107	96	68
Ethiopia	102,403,196	258	21	2
Finland	5,495,096	239	533	Not Known
France	66,896,109	7,205	2,055	864
Georgia	3,719,300	320	33	21
Germany	82,667,685	4,358	3,930	Not Known
Ghana	28,206,728	250	2	Not Known
Greece	10,746,740	1,055	1,075	420
Guatemala	16,582,469	222	22	27
Honduras	9,112,867	307	9	6
Hong Kong (China)	7,305,700	131	2	7
Hungary	9,817,958	1,120	1,442	625
India	1,324,171,354	18,353	532	357
Indonesia	261,115,456	1,954	7	2
Iran	80,277,428	6,087	1,516	3,420
Iraq	37,202,572	1,346	324	373
Ireland	4,773,095	853	1,420	998
Jamaica	2,725,941	45	Not Known	Not Known
Japan	126,994,511	6,200	1,222	367
Jordan	9,455,802	367	252	246
Kenya	48,461,567	654	50	13
Korea, Republic of	51,245,707	2,103	126	125
Kyrgyzstan	5,957,000	300	9	3
Latvia	1,960,424	156	120	7
Lebanon	5,850,743	189	107	69
Lesotho	2,203,821	24	Not Known	Not Known
Lithuania	2,872,298	172	303	18
Macedonia	2,078,453	315	167	20
Madagascar	24,894,551	100	2	10

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Malawi	18,091,575	39	0	0
Malaysia	31,187,265	1,595	657	306
Maldives	417,492	17	Not Known	Not Known
Mali	17,994,837	81	4	1
Mauritania	4,067,564	38	2	Not Known
Mauritius	1,263,473	78	0	7
Mexico	127,540,423	5,693	297	45
Moldova	3,554,150	230	6	Not Known
Mongolia	3,027,398	96	13	Not Known
Montenegro	622,781	45	3	5
Morocco	35,276,786	844	17	20
Nepal	28,982,771	573	4	15
New Zealand	4,692,700	447	230	68
Nicaragua	6,149,928	251	77	7
Nigeria	185,989,640	308	4	0
Norway	5,232,929	413	580	77
Oman	4,424,762	133	354	392
Pakistan	193,203,476	1,343	209	94
Palestine	4,422,143	293	35	7
Panama	4,034,119	290	497	65
Paraguay	6,725,308	480	1	1
Peru	31,376,670	887	171	19
Philippines	103,320,222	1,395	38	Not Known
Poland	37,948,016	2,835	1,827	517
Portugal	10,324,611	703	51	15
Qatar	2,569,804	48	32	13
Romania	19,705,301	1,825	87	11
Russia	144,342,396	7,451	1,950	Not Known
Saudi Arabia	32,275,687	418	182	237
Senegal	15,411,614	193	8	5
Serbia	7,057,412	539	286	48
Singapore	5,607,283	252	85	76
Slovak Republic	5,428,704	596	640	1,070
Slovenia	2,064,845	237	182	77

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
South Africa	55,908,865	2,206	632	223
Sri Lanka	21,203,000	863	47	29
Sudan	39,578,828	1,012	254	317
Suriname	542,975	20	5	0
Sweden	9,798,871	1,068	1,512	513
Switzerland	8,372,098	249	Not Known	Not Known
Syria	18,430,453	711	74	77
Tanzania	55,572,201	105	3	Not Known
Thailand	68,863,514	1,521	69	59
Togo	7,606,374	30	Not Known	Not Known
Tunisia	11,403,248	479	142	250
Uganda	41,487,965	138	3	Not Known
Ukraine	45,198,200	2,600	470	Not Known
United Arab Emirates	9,156,963	100	40	31
United Kingdom	65,637,239	8,031	10,627	7,981
United States	323,127,513	16,949	11,118	5,147
Uzbekistan	31,848,200	1,548	91	50
Venezuela	31,568,179	2,750	989	1,007
Vietnam	92,701,100	2,948	118	260
Zambia	16,591,390	90	5	Not Known
Zimbabwe	15,602,751	142	Not Known	Not Known
Total	**6,702,703,202**	**184,723**	**71,648**	**39,495**

Table 7. Distribution of reported bleeding disorders by country

Please 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 2016.

	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
Afghanistan	289	17														
Albania	161	27	1	4					3	2		1				
Algeria	1,798	362		298	42	8	50	22	333	15	8	19		26	13	
Argentina	2,270	360	0	401				1	2		1	1		2		3
Australia	2,075	501		2,092	62		16		67	18	248	38		21	5	247
Austria	658	114	0													
Azerbaijan	1,098	134		207	11		7	31	18	17	7	2	9	5	6	
Bangladesh	770	124	6	2	2							1				
Belarus	455	109		192	0	0			19	3	26					
Belgium	970	233	9	1,906	2	2	20		118	8	128	4	26	19	3	125
Belize	11	5														
Bolivia	160	40		1												
Brazil	10,123	1,996	0	7,811	107	18	191	38	1,054	117	215	67	0	576	75	414
Burkina Faso	36	10														
Cambodia	135	18		4								1				5
Cameroon	153	23		2												
Canada	3,183	710		4,437	92	13	76	4	371	37	425	53		64	28	769
Chile	1,295	138	114	483			26	5	215	26	35			5	4	157
China	12,533	1,857		72	33		5	6	15	6	17	3		5		
Colombia	1,705	354	0	1,471	17	6	31	12	73	3	44	17	36	15	2	26
Costa Rica	178	32	0	71	1		1		17	8	6	3				
Cote d'Ivoire	74	7	0	3	0	0	0	0	1	2	0	0	0	0	0	0
Cuba	400	70	0	351	2	1	2	0	2	2	15	7	17	3	0	3,169
Czech Republic	937	139	0	818		1	8	0	52	2	19	2	25			
Denmark	410	108	0	309	3	0	3	0	52	14	13	6	0	13	7	34
Dominican Republic	264	34	72	17						14		1		1		
Ecuador	125	7	0	48			1					1		1		
Egypt	4,504	1,045	0	543	149	8	174	8	135	113	93	41	0	466	18	
Eritrea	50	4														
Estonia	97	10		96	5		2	1	30		5		15		2	8
Ethiopia	122	18	118	21										2		

	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
Finland	150	33	56	533												
France	5,864	1,341	0	2,055	41	1	52	13	166	24	177	25	0	178	47	140
Georgia	268	52		33	1				8			2		4		6
Germany	3,686	672		3,930												
Ghana	218	5	27	2												
Greece	873	182	0	1,075	23	3	28	1	137	9	95	13	0	17	13	81
Guatemala	134	61	27	22	0	0	0	0	0	0	0	0	0	0	0	0
Honduras	272	29	6	9	0	0	0	0	4	0	1	1	0	0	0	0
Hong Kong (China)	101	23	7	2					2	2						3
Hungary	893	227	0	1,442	16	1	22	0	300	22	77	3	0	3		27
India	15,218	2,379	756	532	25	8	51	12	50	33	30	91		31	26	
Indonesia	1,465	194	295	7								1			1	
Iran	5,008	1,079	0	1,516	139	24	212	229	690	177	223	593	186	559	95	293
Iraq	1,006	340		324	57	2	9	4	85	25	12	49				130
Ireland	617	236	0	1,420	0	0	160	2	180	141	180	11	0	12	3	309
Jamaica	41	4														
Japan	5,103	1,097	0	1,222	74	7	41	9	101	22	40	73				
Jordan	281	86		252		4	13		46	25	42	12		103	1	
Kenya	535	119	0	50	0	0	0	0	1	0	0	0	0	0	0	12
Korea, Republic of	1,683	420		126	5		6	3	41	2	20	5	43			
Kyrgyzstan	273	27		9	1	1								1		
Latvia	129	27	0	120	0	0	0	0	5	0	0	0	2	0	0	0
Lebanon	146	43		107	34		9	1	7	5	5	2		1		5
Lesotho	22	2														
Lithuania	147	24	1	303					11	2		2				3
Macedonia	207	108		167					2		1	5	12			
Madagascar	50	50		2	9											1
Malawi	33	6														
Malaysia	1,360	235	0	657	4	3	21	1	58	24	59	21	0	58	2	55
Maldives	12	4	1													
Mali	78	3	0	4	0	0	0	0	0	0	0	1	0	0	0	0
Mauritania	29	9		2												
Mauritius	65	13	0	0	0	0	0	0	3	1	0	0	0	0	0	3
Mexico	4,659	688	346	297		1	2	2	23	4	4	1	6	2	0	
Moldova	199	21		6												
Mongolia	71	25		13												
Montenegro	41	4	0	3	0	0	0	0	1	0	1	3	0	0	0	0

	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
Morocco	663	181		17	1	1	1	1	3	1	1	2		4	1	4
Nepal	500	73		4		1	1		1	10		2				
New Zealand	365	82	0	230	0	1	0	0	7	1	7	2	23	2	2	23
Nicaragua	216	27	8	77	4								1	2		
Nigeria	301	7	0	4	0	0	0	0	0	0	0	0	0	0	0	0
Norway	325	88		580	2	2	4	0	32	3	1	3		10	4	16
Oman	126	7		354	5	1	8	6	74	6	26	7	22	33	2	202
Pakistan	1,130	209	4	209	6	2	15	1	19	16	0	20	0	13	2	0
Palestine	180	40	73	35		3						2		2		
Panama	258	32	0	497	0	0	0	0	9	16	0	0	0	9	1	30
Paraguay	460	20		1					1							
Peru	712	125	50	171	1	0	1	0	7	1	5	1	2	1	0	0
Philippines	1,015	176	204	38												
Poland	2,413	422		1,827	102	1	26	3	255	24	62	11		25	8	
Portugal	539	112	52	51	2	0	3	0	2	1	6	1				
Qatar	45	3	0	32	0	0	0	0	3	0	0	2	0	5	2	1
Romania	1,615	210		87	1			2	2	2	2		1		1	
Russia	6,342	1,109		1,950												
Saudi Arabia	334	84	0	182	4	13	18	1	14	6	11	35	0	119	6	10
Senegal	174	19	0	8	1	0	1	0	2	1						
Serbia	456	83	0	286	5	0	1	2	25	1	7	4	1	0	2	0
Singapore	207	45	0	85	0	0	18	0	9	0	44	5	0	0	0	0
Slovak Republic	521	75	0	640	89	0	74	1	768	37	51	2	0	10	15	23
Slovenia	207	30	0	182	3	0	12	3	16	2	19	0	0	7	0	15
South Africa	1,848	358	0	632	8	0	45	5	18	9	27	8	6	20	26	51
Sri Lanka	709	154		47			9		2		8	1				9
Sudan	828	184		254	37		49	2	29	28	4	24				144
Suriname	20	0	0	5												
Sweden	860	208		1,512	0	3	2	2	136	19	69	9	1	9	13	250
Syria	642	69		74	16		5	30	12	3				11		
Tanzania	71	13	21	3												
Thailand	1,342	179		69		1	1	1	14	2				40		
Togo	23	4	3													
Tunisia	379	98	2	142	26	0	15	3	62	5	36	24	6	56	8	9
Uganda	119	19		3												
United Arab Emirates	85	15		40					10	1				15	4	1

	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
United Kingdom	6,559	1,472	0	10,627	648	14	206	25	1,231	253	2,960	67	0	132	86	2,359
United States	12,996	3,953		11,118	146	30	104	15	808	93	473	103	1,772	151	40	1,412
Uzbekistan	1,409	139		91	5	5			10		6	8		15	1	
Venezuela	2,184	566		989	20	66	33	28	166	111	384	16	4	15	4	160
Vietnam	2,418	530	0	118	9	3	4	12	37	15	6	12	3	87	5	67
Zambia	63	5	22	5												
Zimbabwe	129	13	0													
Total	**149,764**	**29,712**	**2,281**	**71,178**	**2,098**	**259**	**1,895**	**548**	**8,282**	**1,592**	**6,487**	**1,553**	**2,219**	**2,986**	**584**	**10,811**

Table 8. Gender distribution

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

Disorders	Countries reporting	Total patients identified	Male	Percent male	Female	Percent female	Gender not known	Percent not known
Hemophilia A	**111**	149,764	133,016	**89**	4,062	**3**	12,686	**8**
Hemophilia B	**111**	29,712	25,677	**86**	1,432	**5**	2,603	**9**
Hemophilia type unknown	**64**	2,281	1,719	**75**	169	**7**	393	**17**
von Willebrand disease (VWD)	**100**	71,178	22,747	**32**	37,443	**53**	10,988	**15**
Factor I deficiency	**66**	2,098	862	**41**	1,054	**50**	182	**9**
Factor II deficiency	**58**	259	120	**46**	123	**47**	16	**6**
Factor V deficiency	**66**	1,895	780	**41**	872	**46**	243	**13**
Factor V+VIII deficiency	**61**	548	291	**53**	236	**43**	21	**4**
Factor VII deficiency	**76**	8,282	3,781	**46**	3,910	**47**	591	**7**
Factor X deficiency	**70**	1,592	707	**44**	683	**43**	202	**13**
Factor XI deficiency	**70**	6,466	2,750	**43**	3,468	**54**	248	**4**
Factor XIII deficiency	**72**	1,553	801	**52**	654	**42**	98	**6**
Bleeding disorder: type unknown	**47**	2,219	1,057	**48**	1,142	**51**	20	**1**
Platelet disorders: Glanzmanns thrombasthenia	**64**	2,986	993	**33**	1,117	**37**	876	**29**
Platelet disorders: Bernard Soulier syndrome	**54**	584	236	**40**	260	**45**	88	**15**
Platelet disorders: other or unknown	**55**	10,811	2,547	**24**	4,282	**40**	3,982	**37**

A woman who has ≤40% of the normal level of clotting factor (FVIII – hemophilia A, FIX – hemophilia B) is considered to be a person with hemophilia. A woman with more than 40 percent clotting factor is considered a carrier and is not included in this report.

Table 9. Number of prevalent and incident cases of inhibitors in Hemophilia A and B

Patients with current clinically significant inhibitors, meaning patients who do not respond to standard treatment.

Please note: a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2016)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2016)
Albania	6	2	2	1
Algeria	64	14	0	
Argentina	85	1	5	0
Australia	61	8	3	0
Austria	22		2	
Azerbaijan	23	2		
Brazil	395	56	13	0
Burkina Faso	0	0	0	0
Cambodia	4	2		
Cameroon	12	0	0	0
Canada	3	11	1	0
Colombia	160	8	16	0
Costa Rica	20	0	0	0
Cote d'Ivoire	11	0	0	0
Cuba	35	0	0	0
Czech Republic	21	5	2	0
Denmark	15	1	1	0
Dominican Republic	11	0	0	0
Ecuador	1	1	0	0
Egypt	88	32	2	0
Estonia	4	0		0
Finland	14	3	0	
France	100	12	5	0
Georgia	8			
Germany	102		30	
Ghana	0	0	0	0

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2016)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2016)
Greece	24	1	4	0
Guatemala	0	0	0	0
Hungary	38		1	
Indonesia	86	1		
Iran	250	27	16	4
Iraq	85	5	3	1
Ireland	12	1	2	0
Japan	109		20	
Kenya	4	1	0	0
Korea, Republic of	43	3	8	0
Latvia	3	1	2	0
Lithuania	9	1	0	0
Madagascar	1	1	0	0
Malawi	0		0	
Malaysia	133	3	3	0
Mali	1	1	0	0
Mauritius	1	0	0	0
Mexico	266		14	
Montenegro	1	0	0	0
Morocco	61	52	18	12
Nepal	12	2		
Nicaragua	2			
Nigeria	1	0	0	0
Norway	13	1	1	0
Oman	19		0	
Pakistan	14	0	0	0
Panama	5	1	0	0
Philippines	12	3	1	0
Poland	149		4	
Qatar	5	1	0	0
Russia	320		3	
Saudi Arabia	48	4	2	
Senegal	7	0	0	0
Serbia	18	0	0	0

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2016)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2016)
Singapore	9	0	0	0
Slovak Republic	6	0	1	1
Slovenia	3	0	0	0
South Africa	167	11	12	1
Sri Lanka	47	31	0	0
Sudan	4	2		
Syria	35		1	
Tanzania	5			
Thailand	52	3	1	0
Tunisia	24	4	1	0
Uganda	0		0	
United Kingdom	232	32	12	0
United States	811		64	
Uzbekistan	38			
Venezuela	106	4	4	0
Vietnam	155	72	0	0
Total	**4,711**	**427**	**280**	**20**

Table 10. Age distribution: Hemophilia A

(85 countries reported age data.)

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
Afghanistan	289	20%	42%	16%	22%	1%	0%
Albania	161	2%	16%	11%	47%	25%	0%
Argentina	2,270	4%	17%	9%	46%	21%	4%
Australia	2,075	6%	15%	7%	39%	33%	0%
Austria	658	3%	10%	9%	42%	37%	0%
Azerbaijan	1,098	5%	11%	6%	51%	27%	0%
Bangladesh	770	8%	32%	23%	33%	4%	0%
Belgium	970	2%	11%	8%	36%	42%	0%
Belize	11	9%	18%	36%	36%	0%	0%
Bolivia	160	0%	31%	25%	19%	1%	24%
Brazil	10,123	5%	16%	11%	49%	18%	0%
Burkina Faso	36	19%	47%	11%	14%	0%	8%
Cambodia	135	15%	46%	19%	20%	0%	0%
Cameroon	153	14%	22%	25%	17%	1%	20%
Canada	3,183	3%	13%	8%	42%	34%	0%
China	12,533	3%	20%	13%	49%	15%	1%
Colombia	1,705	8%	25%	14%	38%	15%	0%
Costa Rica	178	4%	19%	15%	51%	11%	1%
Cote d'Ivoire	74	12%	26%	31%	26%	5%	0%
Cuba	400	5%	12%	14%	54%	15%	0%
Czech Republic	937	5%	11%	7%	45%	32%	0%
Denmark	410	5%	13%	7%	35%	40%	0%
Dominican Republic	264	11%	19%	17%	44%	10%	0%
Ecuador	125	0%	2%	11%	68%	19%	0%
Egypt	4,504	8%	42%	4%	10%	2%	33%
Eritrea	50	0%	22%	22%	50%	2%	4%
Estonia	97	5%	9%	4%	61%	21%	0%
Ethiopia	122	7%	38%	17%	37%	2%	0%
France	5,864	8%	17%	10%	40%	26%	0%
Georgia	268	9%	17%	7%	47%	20%	0%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
Ghana	218	7%	45%	21%	11%	2%	14%
Greece	873	3%	8%	7%	38%	44%	0%
Guatemala	134	8%	25%	19%	40%	7%	0%
Honduras	272	8%	29%	15%	36%	3%	9%
Hungary	893	3%	7%	5%	44%	41%	0%
India	15,218	2%	15%	11%	36%	7%	28%
Indonesia	1,465	6%	29%	18%	29%	2%	16%
Iran	5,008	4%	13%	8%	57%	18%	0%
Iraq	1,006	23%	38%	19%	17%	2%	0%
Ireland	617	9%	17%	8%	38%	29%	0%
Japan	5,103	5%	13%	7%	43%	32%	0%
Kenya	535	30%	29%	16%	8%	12%	4%
Korea, Republic of	1,683	4%	13%	10%	52%	20%	0%
Latvia	129	5%	15%	5%	47%	28%	0%
Lesotho	22	0%	27%	41%	9%	0%	23%
Madagascar	50	4%	44%	18%	32%	2%	0%
Malaysia	1,360	26%	22%	6%	13%	3%	30%
Maldives	12	8%	42%	8%	25%	17%	0%
Mali	78	31%	40%	10%	15%	0%	4%
Mauritius	65	0%	14%	5%	46%	29%	6%
Mexico	4,659	1%	16%	12%	44%	12%	14%
Mongolia	71	15%	41%	4%	35%	4%	0%
Montenegro	41	5%	17%	7%	37%	34%	0%
Morocco	663	3%	16%	26%	34%	21%	0%
Nepal	500	6%	22%	18%	37%	5%	12%
New Zealand	365	3%	16%	8%	39%	23%	11%
Nicaragua	216	15%	35%	19%	30%	2%	0%
Nigeria	301	10%	33%	14%	25%	2%	16%
Oman	126	12%	27%	14%	42%	5%	0%
Pakistan	1,130	4%	16%	12%	63%	4%	0%
Panama	258	5%	15%	9%	55%	17%	0%
Philippines	1,015	2%	14%	15%	47%	7%	14%
Poland	2,413	2%	8%	5%	48%	37%	0%
Portugal	539	1%	9%	8%	41%	33%	8%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
Qatar	45	18%	27%	24%	29%	2%	0%
Saudi Arabia	334	23%	37%	17%	24%	0%	0%
Senegal	174	11%	32%	16%	40%	1%	0%
Serbia	456	4%	11%	8%	47%	31%	0%
Singapore	207	6%	9%	9%	41%	35%	0%
Slovak Republic	521	4%	10%	5%	47%	33%	0%
Slovenia	207	1%	10%	3%	42%	44%	0%
South Africa	1,848	4%	18%	10%	44%	23%	2%
Sri Lanka	709	18%	18%	6%	24%	4%	29%
Sudan	828	21%	33%	14%	29%	3%	0%
Syria	642	13%	29%	16%	37%	5%	1%
Thailand	1,342	22%	31%	23%	14%	10%	0%
Togo	23	22%	26%	13%	26%	4%	9%
Tunisia	379	8%	22%	8%	52%	5%	6%
Uganda	119	26%	42%	8%	20%	3%	0%
United Kingdom	6,559	6%	12%	8%	38%	36%	0%
United States	12,996	9%	25%	13%	33%	20%	0%
Uzbekistan	1,409	5%	19%	18%	51%	7%	0%
Venezuela	2,184	4%	14%	9%	39%	16%	19%
Vietnam	2,418	7%	23%	11%	51%	9%	0%
Zambia	63	19%	25%	21%	30%	5%	0%

Table 11. Age distribution: Hemophilia B

(85 countries reported age data.)

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
Afghanistan	17	18%	41%	18%	24%	0%	0%
Albania	27	7%	7%	4%	67%	15%	0%
Argentina	360	6%	18%	7%	44%	17%	8%
Australia	501	4%	14%	7%	39%	37%	0%
Austria	114	4%	11%	6%	42%	37%	0%
Azerbaijan	134	10%	23%	10%	43%	14%	0%
Bangladesh	124	8%	38%	27%	26%	2%	0%
Belgium	233	3%	10%	7%	33%	47%	0%
Belize	5	0%	0%	40%	60%	0%	0%
Bolivia	40	0%	25%	20%	13%	0%	43%
Brazil	1,996	5%	15%	13%	47%	19%	0%
Burkina Faso	10	0%	40%	20%	30%	0%	10%
Cambodia	18	17%	56%	6%	22%	0%	0%
Cameroon	23	26%	30%	30%	13%	0%	0%
Canada	710	2%	10%	5%	41%	41%	0%
China	1,857	3%	4%	26%	50%	17%	1%
Colombia	354	9%	23%	10%	38%	20%	0%
Costa Rica	32	0%	16%	9%	66%	9%	0%
Cote d'Ivoire	7	0%	29%	29%	29%	14%	0%
Cuba	70	3%	13%	14%	50%	20%	0%
Czech Republic	139	6%	12%	6%	35%	40%	0%
Denmark	108	7%	9%	6%	34%	39%	0%
Dominican Republic	34	6%	12%	18%	62%	3%	0%
Ecuador	7	0%	0%	0%	100%	0%	0%
Egypt	1,045	5%	43%	2%	7%	1%	42%
Eritrea	4	0%	50%	0%	50%	0%	0%
Estonia	10	10%	30%	0%	30%	30%	0%
Ethiopia	18	11%	33%	11%	39%	6%	0%
France	1,341	9%	19%	10%	37%	26%	0%
Georgia	52	13%	13%	6%	44%	23%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
Ghana	5	0%	0%	100%	0%	0%	0%
Greece	182	4%	7%	4%	38%	48%	0%
Guatemala	61	7%	20%	25%	44%	5%	0%
Honduras	29	7%	24%	14%	38%	3%	14%
Hungary	227	1%	4%	7%	45%	43%	0%
India	2,379	2%	13%	13%	41%	9%	22%
Indonesia	194	11%	36%	23%	22%	3%	7%
Iran	1,079	4%	11%	8%	59%	18%	0%
Iraq	340	18%	36%	23%	16%	7%	0%
Ireland	236	5%	17%	9%	39%	30%	0%
Japan	1,097	4%	12%	7%	42%	34%	0%
Kenya	119	18%	24%	29%	24%	3%	2%
Korea, Republic of	420	5%	17%	12%	45%	21%	0%
Latvia	27	0%	19%	0%	59%	19%	4%
Lesotho	2	50%	50%	0%	0%	0%	0%
Madagascar	50	12%	52%	6%	30%	0%	0%
Malaysia	235	34%	25%	4%	22%	3%	13%
Maldives	4	75%	0%	25%	0%	0%	0%
Mali	3	100%	0%	0%	0%	0%	0%
Mauritius	13	8%	15%	31%	23%	23%	0%
Mexico	688	2%	16%	11%	48%	11%	12%
Mongolia	25	12%	32%	28%	20%	8%	0%
Montenegro	4	0%	0%	50%	25%	25%	0%
Morocco	181	5%	14%	39%	20%	23%	0%
Nepal	73	12%	33%	15%	29%	8%	3%
New Zealand	82	2%	12%	2%	37%	35%	11%
Nicaragua	27	11%	22%	33%	30%	4%	0%
Nigeria	7	43%	29%	14%	14%	0%	0%
Oman	7	14%	29%	0%	57%	0%	0%
Pakistan	209	8%	16%	7%	66%	3%	0%
Panama	32	9%	9%	22%	53%	6%	0%
Philippines	176	4%	18%	13%	48%	7%	10%
Poland	422	2%	8%	5%	50%	34%	1%
Portugal	112	1%	9%	6%	39%	37%	8%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
Qatar	3	0%	0%	100%	0%	0%	0%
Saudi Arabia	84	15%	38%	7%	39%	0%	0%
Senegal	19	26%	53%	11%	5%	5%	0%
Serbia	83	5%	19%	11%	42%	23%	0%
Singapore	45	0%	20%	7%	53%	20%	0%
Slovak Republic	75	5%	17%	7%	49%	21%	0%
Slovenia	30	3%	10%	3%	40%	43%	0%
South Africa	358	5%	20%	9%	41%	23%	1%
Sri Lanka	154	17%	23%	11%	9%	3%	36%
Sudan	184	21%	43%	12%	23%	1%	0%
Syria	69	3%	33%	25%	35%	1%	3%
Thailand	179	26%	30%	20%	12%	13%	0%
Togo	4	0%	25%	0%	0%	0%	75%
Tunisia	98	13%	24%	2%	39%	8%	13%
Uganda	19	5%	42%	21%	32%	0%	0%
United Kingdom	1,472	6%	12%	7%	40%	35%	0%
United States	3,953	9%	24%	11%	29%	26%	0%
Uzbekistan	139	4%	18%	17%	55%	6%	0%
Venezuela	566	3%	13%	7%	39%	20%	19%
Vietnam	530	10%	21%	14%	44%	11%	0%
Zambia	5	0%	20%	0%	80%	0%	0%

Table 12. Age distribution: Hemophilia Type Unknown

(17 countries reported age data.)

	Hemophilia Type Unknown	0–4	5–13	14–18	19–44	45+	Age Not Known
Bangladesh	6	0%	0%	100%	0%	0%	0%
Belgium	9	0%	0%	0%	22%	67%	11%
Dominican Republic	72	3%	22%	19%	35%	8%	13%
Ethiopia	118	25%	27%	23%	25%	0%	0%
Ghana	27	19%	11%	52%	19%	0%	0%
Guatemala	27	11%	26%	26%	22%	15%	0%
Honduras	6	0%	33%	17%	50%	0%	0%
India	756	1%	5%	6%	21%	5%	62%
Indonesia	295	4%	6%	7%	17%	1%	65%
Maldives	1	0%	0%	0%	0%	100%	0%
Mexico	346	1%	7%	5%	21%	5%	61%
Nicaragua	8	25%	63%	13%	0%	0%	0%
Pakistan	4	0%	0%	0%	100%	0%	0%
Philippines	204	4%	11%	12%	41%	4%	27%
Portugal	52	0%	0%	8%	21%	29%	42%
Togo	3	67%	0%	0%	0%	0%	33%
Zambia	22	0%	0%	27%	14%	18%	41%

Table 13. Age distribution: VWD

(71 countries reported age data.)

	VWD	0–4	5–13	14–18	19–44	45+	Age Not Known
Albania	4	0%	0%	0%	100%	0%	0%
Argentina	401	0%	2%	3%	47%	34%	14%
Australia	2,092	2%	10%	7%	44%	36%	0%
Azerbaijan	207	3%	9%	10%	57%	20%	0%
Bangladesh	2	50%	0%	0%	50%	0%	0%
Belgium	1,906	1%	15%	10%	40%	34%	1%
Bolivia	1	0%	0%	0%	100%	0%	0%
Brazil	7,811	1%	11%	10%	52%	25%	0%
Cambodia	4	25%	75%	0%	0%	0%	0%
Canada	4,437	1%	7%	8%	49%	36%	0%
China	72	4%	22%	11%	53%	10%	0%
Colombia	1,471	0%	16%	11%	15%	58%	0%
Cote d'Ivoire	3	0%	0%	0%	100%	0%	0%
Cuba	351	1%	10%	19%	50%	21%	0%
Czech Republic	818	1%	8%	6%	46%	40%	0%
Denmark	309	1%	7%	3%	40%	40%	0%
Dominican Republic	17	12%	18%	12%	53%	6%	0%
Ecuador	48	0%	0%	8%	69%	23%	0%
Egypt	543	6%	45%	3%	1%	1%	44%
Estonia	96	2%	23%	11%	42%	13%	9%
France	2,055	5%	15%	11%	40%	29%	0%
Georgia	33	3%	24%	9%	36%	27%	0%
Ghana	2	0%	100%	0%	0%	0%	0%
Greece	1,075	2%	13%	9%	42%	35%	0%
Guatemala	22	5%	50%	14%	27%	5%	0%
Honduras	9	0%	0%	33%	22%	0%	44%
Hungary	1,442	1%	6%	6%	44%	42%	1%
India	532	2%	15%	12%	43%	7%	21%
Indonesia	7	14%	14%	14%	57%	0%	0%
Iran	1,516	4%	18%	10%	55%	14%	0%

	VWD	0–4	5–13	14–18	19–44	45+	Age Not Known
Iraq	324	17%	31%	40%	10%	3%	0%
Ireland	1,420	6%	18%	7%	46%	24%	0%
Japan	1,222	2%	6%	7%	47%	32%	5%
Kenya	50	20%	26%	28%	14%	4%	8%
Korea, Republic of	126	1%	13%	11%	56%	19%	0%
Latvia	120	3%	0%	1%	57%	39%	0%
Madagascar	2	0%	0%	0%	100%	0%	0%
Malaysia	657	11%	25%	9%	38%	4%	12%
Mali	4	0%	0%	50%	25%	25%	0%
Mexico	297	1%	12%	10%	41%	10%	26%
Mongolia	13	0%	38%	8%	38%	15%	0%
Montenegro	3	0%	0%	33%	67%	0%	0%
Morocco	17	0%	24%	41%	35%	0%	0%
Nepal	4	0%	50%	0%	25%	25%	0%
New Zealand	230	1%	6%	8%	38%	25%	22%
Nicaragua	77	4%	44%	18%	26%	8%	0%
Nigeria	4	25%	50%	0%	25%	0%	0%
Pakistan	209	3%	25%	15%	54%	3%	0%
Panama	497	2%	22%	32%	37%	8%	0%
Paraguay	1	0%	0%	0%	100%	0%	0%
Philippines	38	0%	11%	5%	26%	0%	58%
Poland	1,827	1%	18%	9%	47%	24%	1%
Portugal	51	2%	4%	4%	37%	49%	4%
Qatar	32	13%	16%	53%	19%	0%	0%
Saudi Arabia	182	16%	33%	25%	26%	0%	0%
Senegal	8	0%	50%	25%	25%	0%	0%
Serbia	286	1%	9%	5%	52%	32%	0%
Singapore	85	1%	13%	0%	46%	40%	0%
Slovak Republic	640	1%	6%	4%	56%	32%	0%
Slovenia	182	1%	7%	10%	52%	30%	0%
South Africa	632	0%	6%	7%	43%	39%	4%
Sri Lanka	47	13%	17%	4%	9%	2%	55%
Sudan	254	24%	40%	14%	19%	4%	0%
Syria	74	7%	32%	11%	43%	7%	0%

	VWD	0–4	5–13	14–18	19–44	45+	Age Not Known
Uganda	3	0%	100%	0%	0%	0%	0%
United Kingdom	10,627	3%	11%	6%	41%	39%	0%
United States	11,118	6%	32%	22%	23%	17%	0%
Uzbekistan	91	3%	8%	19%	62%	9%	0%
Venezuela	989	1%	15%	10%	40%	16%	19%
Vietnam	118	7%	23%	16%	40%	14%	0%
Zambia	5	0%	40%	20%	0%	40%	0%

Table 14. HIV and HCV infection

(People currently living with HIV or HCV. 68 countries reported HIV and HCV data.)

Please note: the number of people infected with HCV does not refer to the number of people with active HCV.

Data on HIV and HCV are based on a small number of countries and do not reflect the true global burden of these infections in the bleeding disorders community.

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Afghanistan	0	0	0	8	0	0	1	0	0
Albania	1	0	0	15	0	0	1	0	0
Algeria	0	0	0	26	15	2	12	5	1
Argentina	57	0		611	21				
Austria	49			206					
Burkina Faso	0	0	0	0	0	0	0	0	0
Cameroon	0	0	0	0	0	0	0	0	0
Colombia	12	1	0	192	50	6	92	12	2
Costa Rica	11	0	0	50	0	0	15	0	0
Cote d'Ivoire	1	0	0	1	0	0	0	0	0
Czech Republic	3	0	0	210	2	0	60	1	0
Dominican Republic	0	0	0	12	0	0		0	0
Ecuador	0	0	0	0	0	0	0	0	0
Estonia	0	0	0	28	1				
Finland	0								
France	523	16	3	2,000	173	46			
Georgia				144			136		
Germany	370			2,000					
Ghana	0	0	0	0	0	0	0	0	0
Greece	51	2	0	272	26	9	126	10	3
Hungary	10			389	108				
India	149								
Indonesia	1			39					

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Iraq				300	62	5			
Ireland	31	0	0	138	7	7	4	0	0
Japan	714	7	3	2,496	146	86	1,789	115	67
Kenya	23	2	0						
Korea, Republic of	18			557			108		
Latvia				36					
Lithuania	0	0	0		0	0		0	0
Madagascar	0	0	0	1	0	0	1	0	0
Malaysia	2	0	0	0	0	0	0	0	0
Maldives	0	0	0	0	0	0	0	0	0
Mali	0	0	0	0	0	0	0	0	0
Mauritius	0	0	0	8	0	0	8	0	0
Mexico	49	3	0	269	7	2			
Montenegro	0	0	0	3	0	0	1	0	0
Morocco	0	0	0	30	0	0	0	0	0
Nepal	1			8					
New Zealand	6	0	0	137	1	0	14	0	0
Nicaragua	1	0	0	18	0	0	0	0	0
Norway	5	0	0						
Oman	2			16					
Pakistan	13	1	0	182	49	0	182	49	0
Panama	0	0	0	23	5	0	20	5	0
Philippines	0								
Qatar	0	0	0	0	0	0	0	0	0
Saudi Arabia	31	0	0	88	0	0			0
Senegal	0	0	0	0	0	0	0	0	0
Serbia	7	2	0	122	7	1			
Singapore	0	0		64	2				
Slovak Republic	0	0	0	131	22	16	24	2	0
Slovenia	7	0	0	78	6	3	8	0	0

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
South Africa	71	3	0	217	4	2	17	4	2
Sri Lanka	0	0	0	1					
Sudan	2			40					
Switzerland	12			68					
Syria				71	6				
Thailand	3			60					
Togo	0								
Tunisia	10	0	0	71			2		
Uganda	1			1					
United Kingdom	278	4	0	1,246	132	19			
United States	939	15	5				2,227	106	29
Uzbekistan	9			177	11				
Venezuela	84	9	1	320	24		60	8	
Vietnam	3	0	0	199	3	22	0	0	0
Zambia	1	0	0	0	0	0	0	0	0
Total	**3,561**	**65**	**12**	**13,379**	**890**	**226**	**4,908**	**317**	**104**

** Hepatitis C antibody positive at any time*

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

Table 15. Percentage of patients on prophylaxis

(79 countries reported prophylaxis data.)

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

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Albania	0%	Estimate	0%	Estimate
Algeria	90%	Estimate	15%	Estimate
Argentina	75%	Estimate	5%	Estimate
Australia	90%	Estimate	68%	Estimate
Austria	90%	Precise	63%	Precise
Azerbaijan	55%	Precise	1%	Estimate
Belgium	90%	Estimate	75%	Estimate
Belize	0%	Precise	0%	Precise
Bolivia	0%	Precise	0%	Precise
Brazil	77%	Precise	31%	Precise
Burkina Faso	13%	Precise	3%	Precise
Cambodia	50%	Estimate		
Cameroon	2%	Precise	0%	Precise
China	5%	Estimate		
Colombia	86%	Precise	72%	Precise
Costa Rica	20%	Precise	55%	Precise
Cote d'Ivoire	0%	Precise	0%	Precise
Cuba	15%	Precise	0%	Precise
Czech Republic	86%	Precise	57%	Precise
Denmark	100%	Estimate	40%	Estimate
Dominican Republic	12%	Precise	0%	Precise
Ecuador			10%	Estimate
Egypt	1%	Estimate	1%	Estimate
Eritrea	78%	Precise	37%	Precise
Estonia	100%	Precise	28%	Precise
Ethiopia	0%	Estimate	0%	Estimate
Finland	90%	Estimate		
France	79%	Precise	51%	Precise
Georgia	10%	Estimate	12%	Estimate
Germany	100%	Estimate		

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Ghana	80%	Estimate	80%	Estimate
Greece	87%	Precise	29%	Estimate
Honduras	0%	Estimate	0%	Estimate
Hungary	100%	Precise	70%	Estimate
Indonesia	0%	Precise	0%	Precise
Iran	20%	Precise	0%	Precise
Iraq	80%	Estimate	10%	Estimate
Ireland	96%	Precise	73%	Precise
Japan	90%	Estimate	72%	Estimate
Kenya	14%	Precise	1%	Precise
Latvia	100%	Estimate	100%	Estimate
Lesotho	0%	Estimate	0%	Estimate
Lithuania	100%	Precise	25%	Estimate
Madagascar	10%	Estimate	10%	Estimate
Malaysia	60%	Estimate	51%	Estimate
Mali	6%	Precise	0%	Precise
Mauritius	100%	Precise	58%	Precise
Mongolia	0%	Estimate	0%	Estimate
Montenegro	78%	Precise	67%	Precise
Morocco	20%	Estimate	30%	Estimate
New Zealand	100%	Precise	50%	Estimate
Nicaragua	0%	Precise	0%	Precise
Nigeria	15%	Precise	0%	Precise
Norway	100%	Estimate	80%	Estimate
Pakistan	1%	Precise	0%	Precise
Panama	100%	Precise	100%	Precise
Philippines	1%	Estimate	1%	Estimate
Poland	100%	Precise		
Qatar	50%	Precise	70%	Precise
Romania	90%	Estimate	0%	Estimate
Russia	55%	Estimate	40%	Estimate
Senegal	18%	Estimate	0%	Estimate
Serbia	90%	Estimate	34%	Estimate
Singapore	95%	Estimate	30%	Estimate
Slovak Republic	95%	Precise	40%	Estimate
Slovenia	77%	Precise	64%	Precise

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
South Africa	35%	Estimate	25%	Estimate
Sri Lanka	24%	Precise	6%	Estimate
Switzerland	95%	Estimate	50%	Estimate
Syria	0%	Precise		
Tanzania	0%	Estimate	0%	Estimate
Thailand	20%	Estimate	10%	Estimate
Togo	0%	Estimate	0%	Estimate
Tunisia	50%	Estimate		
Uganda	1%	Precise	1%	Precise
United Kingdom	95%	Estimate	70%	Estimate
Uzbekistan	0%	Estimate	0%	Estimate
Venezuela	20%	Estimate	15%	Estimate
Vietnam	30%	Estimate	2%	Estimate

Table 16. Reported Use of Factor Concentrates in 2016: Factor VIII

(91 countries reported Factor VIII data.)

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 based on an estimate or from one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2016 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. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2016.

	Factor VIII Total IU	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Afghanistan	1,500,000	400,000	250,000	850,000	0.043	0.019	62	38
Albania	4,500,000	No data	No data	3,000,000	1.565	0.522		
Algeria	76,783,000	38,419,500	38,363,500	No data	1.891	1.891	50	50
Argentina	192,250,000	115,000,000	74,000,000	3,250,000	4.385	4.31	61	39
Australia	161,387,800	15,139,250	146,248,550	0	6.689	6.689	9	91
Azerbaijan	18,000,000	18,000,000	0	0	1.844	1.844	100	
Bangladesh	800,000	No data	No data	800,000	0.005			
Belize	391,138	No data	No data	391,138	1.066			
Bolivia	225,000	No data	No data	No data	0.021	0.021		
Brazil	738,410,000	212,705,000	525,705,000	0	3.556	3.556	29	71
Burkina Faso	107,500	0	0	107,500	0.006	0	0	0
Cambodia	725,000	No data	No data	725,000	0.046			
Cameroon	1,225,000	No data	No data	1,225,000	0.052			
Canada	291,584,987	55,606,254	235,978,733	0	8.036	8.036	19	81
Colombia	247,325,500	130,102,250	117,168,250	55,000	5.083	5.082	53	47
Costa Rica	15,726,500	15,726,500	0	No data	3.238	3.238	100	0
Cote d'Ivoire	752,500	0	0	752,500	0.032	0	0	0
Cuba	6,505,000	5,505,000	0	1,000,000	0.567	0.48	100	0
Czech Republic	59,791,435	27,827,829	31,963,606	0	5.661	5.661	47	53
Denmark	20,453,200	0	20,453,200	0	3.569	3.569	0	100
Dominican Republic	5,625,000	No data	No data	975,000	0.528	0.437		

	Factor VIII Total IU	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Ecuador	3,184,750	No data	No data	No data	0.194	0.194		
Egypt	24,550,260	19,675,260	250,000	4,625,000	0.257	0.208	99	1
Eritrea	614,186	0	0	614,186	0.105	0	0	0
Ethiopia	1,162,000	0	0	1,162,000	0.011	0	0	0
Finland	47,305,000	7,946,000	39,359,000	0	8.609	8.609	17	83
France	489,000,000	73,350,000	415,650,000	0	7.31	7.31	15	85
Georgia	7,550,000	7,550,000	No data	No data	2.03	2.03	100	
Germany	585,494,745	227,656,025	357,838,720	0	7.083	7.083	39	61
Ghana	1,127,000	0	0	1,127,000	0.04	0	0	0
Greece	44,932,750	6,282,750	38,650,000	0	4.181	4.181	14	86
Guatemala	236,510	No data	No data	236,510	0.014			
Honduras	9,539,500	0	0	546,000	1.047	0.987	0	0
Hungary	102,277,000	63,186,000	39,091,000	No data	10.417	10.417	62	38
India	138,976,140	81,500,389	14,000,000	43,475,751	0.105	0.072	85	15
Indonesia	30,779,000	28,679,000	No data	2,100,000	0.118	0.11	100	
Iran	180,000,000	No data	No data	No data	2.242	2.242		
Iraq	45,000,000	0	45,000,000	0	1.21	1.21	0	100
Ireland	51,744,000	4,479,500	47,264,500	0	10.841	10.841	9	91
Japan	732,200,000	84,900,000	647,300,000	0	5.766	5.766	12	88
Jordan	1,602,096	No data	No data	1,602,096	0.169			
Kenya	6,668,000	0	0	6,668,000	0.138	0	0	0
Korea, Republic of	239,495,000	55,342,000	184,153,000	0	4.673	4.673	23	77
Latvia	6,396,000	4,447,000	1,949,000	0	3.263	3.263	70	30
Lesotho	5,542	No data	No data	5,542	0.003			
Lithuania	16,928,750	9,921,500	7,007,250	No data	5.894	5.894	59	41
Madagascar	875,000	No data	No data	875,000	0.035			
Malawi	11,101	0	0	11,101	0.001	0	0	0
Malaysia	8,490,750	7,953,500	537,250	0	0.272	0.272	94	6
Maldives	60,550	0	0	60,550	0.145	0	0	0
Mali	999,300	0	0	999,300	0.056	0	0	0
Mauritius	2,215,000	2,078,000	0	137,000	1.753	1.645	100	0

	Factor VIII Total IU	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Mexico	181,694,344	163,647,250	18,011,750	35,344	1.425	1.424	90	10
Mongolia	1,791,500	No data	950,000	841,500	0.592	0.314		100
Montenegro	1,250,000	1,250,000	0	0	2.007	2.007	100	0
Morocco	18,230,000	9,876,500	7,014,250	1,339,250	0.517	0.479	58	42
Nepal	3,099,690	No data	No data	3,099,690	0.107			
New Zealand	25,377,600	3,977,500	21,400,100	0	5.408	5.408	16	84
Nicaragua	1,500,000	0	0	1,500,000	0.244	0	0	0
Nigeria	4,024,420	No data	No data	4,024,420	0.022			
Pakistan	3,975,000	No data	No data	3,975,000	0.021			
Panama	3,343,723	3,342,600	1,123	0	0.829	0.829	100	0
Paraguay	208,000	No data	No data	208,000	0.031			
Philippines	6,496,676	2,460,500	0	4,036,176	0.063	0.024	100	0
Poland	242,003,000	234,151,000	7,852,000	0	6.377	6.377	97	3
Portugal	64,954,250	27,050,000	37,904,250	No data	6.291	6.291	42	58
Qatar	350,000	0	350,000	0	0.136	0.136	0	100
Romania	26,012,250	17,418,300	8,550,750	43,200	1.32	1.318	67	33
Russia	697,223,678	605,782,978	91,440,700	0	4.83	4.83	87	13
Saudi Arabia	92,575,000	36,225,000	56,350,000	No data	2.868	2.868	39	61
Senegal	1,822,500	0	0	1,822,500	0.118	0	0	0
Serbia	20,922,600	12,107,350	8,815,250	0	2.965	2.965	58	42
Singapore	7,033,250	4,396,250	2,637,000	No data	1.254	1.254	63	37
Slovak Republic	38,500,000	34,000,000	4,500,000	0	7.092	7.092	88	12
Slovenia	16,959,250	4,663,750	12,295,500	0	8.213	8.213	27	73
South Africa	58,630,250	57,069,500	1,560,750	0	1.049	1.049	97	3
Sri Lanka	3,162,500	No data	No data	3,162,500	0.149			
Sudan	6,611,900	5,311,900	No data	1,300,000	0.167	0.134	100	
Switzerland	51,618,357	10,553,250	41,065,107	No data	6.166	6.166	20	80
Syria	1,224,000	0	0	1,224,000	0.066	0	0	0
Tanzania	200,000	No data	No data	200,000	0.004			
Thailand	19,428,750	No data	No data	1,380,750	0.282	0.262		
Togo	55,700	No data	No data	55,700	0.007			

	Factor VIII Total IU	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Tunisia	10,021,250	7,042,750	2,478,500	500,000	0.879	0.835	74	26
Uganda	948,410	No data	No data	948,410	0.023			
United Kingdom	569,222,664	38,103,905	531,118,759	0	8.672	8.672	7	93
United States	3,080,000,000	405,000,000	2,675,000,000	No data	9.532	9.532	13	87
Uzbekistan	3,446,900	No data	No data	3,437,500	0.108	0		
Venezuela	78,642,560	13,410,030	53,100,000	12,132,530	2.491	2.107	20	80
Vietnam	20,910,300	18,010,300	0	2,900,000	0.226	0.194	100	0
Zambia	200,000	No data	No data	200,000	0.012			
TOTAL	**9,986,083,762**	**3,034,229,120**	**6,611,201,348**	**124,042,644**			**30%**	**66%**

Table 17. Reported Use of Factor Concentrates in 2016: Factor IX

(87 countries reported Factor IX data.)

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 based on an estimate or from one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2016 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. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2016.

	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
Afganistan	0	0	0	0	0	0	0	0
Albania	300,000	No data	No data	0	0.104	0.104		
Algeria	22,046,500	22,046,500	No data	No data	0.543	0.543	100	
Argentina	22,800,000	14,000,000	8,000,000	800,000	0.520	0.502	64	36
Australia	26,251,000	668,000	25,583,000	0	1.088	1.088	3	97
Azerbaijan	2,000,000	2,000,000	0	0	0.205	0.205	100	
Bangladesh	200,000	No data	No data	200,000	0.001			
Belize	318,890	No data	No data	318,890	0.869			
Bolivia	50,000	No data	No data	No data	0.005	0.005		
Brazil	120,081,432	120,081,432	0	0	0.578	0.578	100	0
Burkina Faso	9,657	No data	No data	9,657	0.001			
Cambodia	100,000	No data	No data	100,000	0.006			
Cameroon	100,000	No data	No data	100,000	0.004			
Canada	54,697,909	4,608,076	50,089,833	0	1.507	1.507	8	92
Colombia	35,989,250	21,923,500	14,065,750	0	0.740	0.740	61	39
Costa Rica	3,580,200	3,580,200	0	No data	0.737	0.737	100	0
Cote d'Ivoire	114,150	0	0	114,150	0.005	0	0	0
Cuba	522,500	522,500	0	0	0.046	0.046	100	0
Czech Republic	6,617,556	6,027,050	590,506	0	0.627	0.627	91	9
Denmark	4,811,000	0	4,811,000	0	0.839	0.839	0	100

	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
Dominican Republic	275,000	No data	No data	275,000	0.026			
Ecuador	285,600	No data	No data	No data	0.017	0.017		
Egypt	1,250,000	200,000	250,000	800,000	0.013	0.005	44	56
Eritrea	10,000	No data	No data	10,000	0.002			
Ethiopia	100,000	0	0	100,000	0.001	0	0	0
Finland	9,986,000	9,686,000	300,000	0	1.817	1.817	97	3
France	77,000,000	27,720,000	49,280,000	0	1.151	1.151	36	64
Georgia	1,550,000	1,550,000	No data	No data	0.417	0.417	100	
Germany	69,457,050	38,074,500	31,382,550	0	0.840	0.840	55	45
Ghana	350,000	0	0	350,000	0.012	0	0	0
Greece	5,548,500	404,500	5,144,000	0	0.516	0.516	7	93
Honduras	82,940	0	0	65,440	0.009	0.002	0	0
Hungary	6,500,000	6,500,000	0	No data	0.662	0.662	100	0
India	3,225,000	2,100,000	No data	1,125,000	0.002	0.002	100	
Indonesia	2,178,500	1,678,500	No data	500,000	0.008	0.006	100	
Iran	25,000,000	No data	No data	No data	0.311	0.311		
Iraq	10,000,000	0	10,000,000	0	0.269	0.269	0	100
Ireland	12,034,600	328,000	11,706,600	0	2.521	2.521	3	97
Japan	128,700,000	57,200,000	71,500,000	0	1.013	1.013	44	56
Jordan	22,460	No data	No data	22,460	0.002			
Kenya	600,000	0	0	600,000	0.012	0	0	0
Korea, Republic of	55,017,000	3,505,000	51,512,000	0	1.074	1.074	6	94
Latvia	726,500	726,500	0	0	0.371	0.371	100	0
Lithuania	3,200,400	3,200,400	0	No data	1.114	1.114	100	0
Madagascar	425,000	No data	No data	425,000	0.017			
Malawi	0	0	0	0	0.000	0	0	0
Malaysia	1,276,050	1,276,050	0	0	0.041	0.041	100	0
Maldives	125,000	0	0	125,000	0.299	0	0	0
Mali	50,000	0	0	50,000	0.003	0	0	0
Mauritius	289,312	283,000	0	6,312	0.229	0.224	100	0

	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
Mexico	34,779,800	34,465,900	284,500	29,400	0.273	0.272	99	1
Mongolia	425,000	No data	300,000	125,000	0.140	0.099		100
Montenegro	142,500	142,500	0	0	0.229	0.229	100	0
Morocco	1,914,500	674,000	1,090,500	150,000	0.054	0.050	38	62
Nepal	349,000	No data	No data	349,000	0.012			
New Zealand	3,734,750	725,000	3,009,750	0	0.796	0.796	19	81
Nicaragua	100,000	0	0	100,000	0.016	0	0	0
Nigeria	400,000	No data	No data	400,000	0.002			
Pakistan	900,000	No data	No data	900,000	0.005			
Panama	926,400	926,400	0	0	0.230	0.230	100	0
Philippines	862,490	0	0	862,490	0.008	0	0	0
Poland	33,485,950	31,876,700	1,609,250	0	0.882	0.882	95	5
Portugal	8,793,550	5,131,800	3,661,750	No data	0.852	0.852	58	42
Qatar	30,000	0	30,000	0	0.012	0.012	0	100
Romania	3,805,950	No data	0	No data	0.193	0.193		0
Russia	103,535,740	103,535,740	0	0	0.717	0.717	100	0
Saudi Arabia	12,000,000	7,000,000	5,000,000	No data	0.372	0.372	58	42
Senegal	275,000	0	0	275,000	0.018	0	0	0
Serbia	2,385,100	2,385,100	0	0	0.338	0.338	100	0
Singapore	1,616,500	1,603,500	13,000	No data	0.288	0.288	99	1
Slovak Republic	2,900,000	2,900,000	0	0	0.534	0.534	100	0
Slovenia	1,163,500	598,500	565,000	0	0.563	0.563	51	49
South Africa	9,303,500	9,303,500	0	0	0.166	0.166	100	0
Sri Lanka	900,000	No data	No data	900,000	0.042			
Sudan	1,052,000	1,052,000	No data	No data	0.027	0.027	100	
Switzerland	8,162,300	5,266,800	2,895,500	No data	0.975	0.975	65	35
Tanzania	115,000	No data	No data	115,000	0.002			
Thailand	2,304,000	No data	No data	0	0.033	0.033		
Togo	4,020	No data	No data	4,020	0.001			
Tunisia	971,500	971,500	0	0	0.085	0.085	100	0
Uganda	163,860	No data	No data	163,860	0.004			

	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
United Kingdom	94,958,422	8,660,530	86,297,892	0	1.447	1.447	9	91
United States	535,000,000	63,000,000	472,000,000	No data	1.656	1.656	12	88
Uzbekistan	951,100	No data	No data	950,000	0.030	0		
Venezuela	14,278,000	10,478,000	1,900,000	1,900,000	0.452	0.392	85	15
Vietnam	846,760	546,760	0	300,000	0.009	0.006	100	0
Zambia	50,000	No data	No data	50,000	0.003			
TOTAL:	**1,599,691,148**	**641,133,938**	**913,122,381**	**13,670,679**			**40%**	**57%**

Annual Global Survey **2016**

A. National Hemophilia Organization

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

Please Click Here **to validate Organization contact information**

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

What is the source of the numbers provided for this survey?	**Check one** ☐ Hemophilia Society and/or NMO registry or database ☐ Hospital(s)/HTC(s) registry or database ☐ Health Ministry registry or database ☐ Other (please describe):
How often is your database updated?	☐ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
Who updates the database?	☐ Doctors update the database ☐ Patient organization updates the database ☐ Hospitals or clinics update the database ☐ Other (please describe):
Have all the identified patients in your country been included in this report? If not, please explain.	Yes ☐ No ☐ Please explain:

Please Click Here **to validate Data source**

B. Identified Patients

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

Please Click Here **to validate number of patients**

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

Age group	Number with hemophilia A	Number with hemophilia B	Number with hemophilia type unknown	Number with VWD
0 - 4 years old				
5 - 13 years old				
14 - 18 years old				
19 - 44 years old				
45 years or older				
Patients with age Unknown				
No age data	☐	☐	☐	☐

The age distribution of Hemophilia A, B and unknown should be equal to the number of PWH in question B1
The age distribution of vWD should be equal to the number of vWD in question B2

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

Please Click Here **to validate Age section**

6. Type of hereditary bleeding disorder

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

Diagnosis	Total	Male	Female	Gender unknown	No data
Hemophilia A					☐
Hemophilia B					☐
Hemophilia, type unknown					☐
von Willebrand disease					☐
Factor I deficiency					☐
Factor II deficiency					☐
Factor V deficiency					☐
Factor V+VIII deficiency					☐
Factor VII deficiency					☐
Factor X deficiency					☐
Factor XI deficiency					☐
Factor XIII deficiency					☐
Rare factor deficiency: type unknown					☐
Platelet disorders: Glanzmann's thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

The sum of Totals Hemophilia A, B, and type unknown should be equal to the number of PWH in question B1.
The Total of vWD should be equal to the number of vWD in question B2.
The sum of Total of the all other bleeding and platelets disorders should be equal to the number of OBD in question B3
A woman who has less than 40 percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

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

Please Click Here **to validate Gender section**

Annual Global Survey **2016**

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

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

How are patients with von Willebrand Disease classified?

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

8. Number of identified people with hemophilia by gender and severity

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

- A person (male or female) with >5-40 per cent of the normal amount of clotting factor has **mild** hemophilia.
- A person (male or female) with between 1-5 per cent of the normal amount of clotting factor has **moderate** hemophilia.
- A person (male or female) with less than 1 per cent of the normal amount of clotting factor has **severe** hemophilia.
- A woman who has less than 40 percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

Type of hemophilia	Mild (factor level above 5%)	Moderate (factor level 1% to 5%)	Severe (factor level below 1%)	Severity unknown	No Data
Hemophilia A male					☐
Hemophilia A female					☐
Hemophilia B male					☐
Hemophilia B female					☐

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

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

9. Number of severe VWD patients

Total number of severe (type 3) VWD patients	Number of VWD patients receiving replacement therapy	Number of VWD patients with severe bleeding symptoms	No Data
			☐

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

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

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2016	No Data
Hemophilia A			☐
Hemophilia B			☐

Please Click Here **to validate classification, severity and inhibitors**

11. Availability and usage of products to treat hemophilia

Treatment product	Product is available	Product is used	Number of patients treated with product indicated	No data
Plasma	☐	☐		☐
Cryoprecipitate	☐	☐		☐
Plasma-derived concentrate	☐	☐		☐
Recombinant concentrate (excluding prolonged half-life)	☐	☐		☐
Recombinant concentrate (prolonged half-life)	☐	☐		☐
DDAVP (Desmopressin)	☐	☐		☐

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

12. Availability and usage of products to treat VWD

Treatment product	Product is available	Product is used	Number of patients treated with product indicated	No data
Plasma	☐	☐		☐
Cryoprecipitate	☐	☐		☐
Plasma-derived concentrate	☐	☐		☐
DDAVP (Desmopressin)	☐	☐		☐

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

13. HIV infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people living with HIV			
New HIV infections in 2016			

14. Hepatitis C infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people infected with hepatitis C[1]			
Total number of people with currently active hepatitis C[2]			
New hepatitis C infections in 2016			

[1]Hepatitis C antibody positive at any time

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

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2016)

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			

Please Click Here **to validate products, HIV, HCV, and cause of death sections**

C. Hemophilia Care System in Your Country

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

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

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

17. What percentage of children (under age 18) **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What percentage of adults (over age 18), **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What is the most common dose (IU/kg) of factor administered and frequency?			

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

18. What **percentage** of patients **with inhibitors** are receiving or have ever received immune tolerance induction?		Precise: ☐ Estimate: ☐	Not known ☐
How many patients **with inhibitors** have received immune tolerance induction in the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Please Click Here **to validate Care section**

D. The Cost and Use of Factor Concentrates

19 A. Annual usage of purchased factor concentrates (please do not include donated factor)	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2016 (excluding donated factor)?		☐		☐
How many international units of **plasma-derived** concentrates were used in your country in 2016 (excluding donated factor)?		☐		☐
How many international units of **recombinant** concentrates were used in your country in 2016 (excluding donated factor)?		☐		☐

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

19 B. Annual usage of donated factor concentrates	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
How many international units of **donated factor** concentrates (plasma-derived or recombinant) from all sources, including **Humanitarian Aid,** were used in your country in 2016?		☐		☐

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

PLEASE NOTE: If a product used in your country is not listed, please add it at the bottom of the appropriate table.

Currency:	Tax included? No ☐ Yes ☐	Tax rate:

Please Click Here **to validate Factors section**

20. Factor VIII Concentrates used in 2016

(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	Baxalta (Baxter Bioscience)	
☐	Adynovate	Baxalta (Baxter Bioscience)	
☐	Aleviate	CSL Behring	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Bioclot A	Biofarma	
☐	Beriate P	CSL Behring	
☐	BIOSTATE	CSL Bioplasma	
☐	Conco-eight-HT	Benesis	
☐	Confact F	Kaketsuken	
☐	Cross Eight M	Japanese Red Cross	
☐	Elocta/Eloctate	Biogen Idec	
☐	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	
☐	HEMO-8R	HEMOBRAS	
☐	Hemofil M AHF	Baxalta (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	
☐	Human Coagulation Factor VIII	Baltijas Terapeitiskais Serviss	
☐	Immunate	Baxalta (Baxter Bioscience)	
☐	Koate DVI	Talecris	

☐	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
☐	Monoclate P	CSL Behring	
☐	Novoeight	NovoNordisk	
☐	Nuwiq	Octapharma	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Octavi SD	Octapharma	
☐	Octofactor	Generium/Pharmstandart	
☐	Optivate	Bio Products Laboratory	
☐	FVIII by Quimbiotec	Quimbiotec	
☐	Recombinate rAHF	Baxalta (Baxter Bioscience)	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	TBSF purity factor, Koate DVI	Grifols	
☐	UNC Hemoderivados	Laboratorio de Hemoderivados de Universidad Nacional de Córdoba	
☐	Voncento	CSL Behring	
☐	Western Province factor8 VIAHF	Western Province Blood transfusion Service	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

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

21. Factor IX Concentrates used in 2016

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

Used	Brand Name	Manufacturer	Price per IU
☐	Aimafix	Kedrion	
☐	AlphaNine SD	Grifols	
☐	Alprolix	Biogen Idec	
☐	BeneFIX	Wyeth	
☐	Berinin-P = Berinin HS	CSL Behring	
☐	BETAFACT	LFB	
☐	Christmassin-M	Benesis	
☐	Clotnine	Hemarus	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Fixnove	Baxalta (Baxter Bioscience)	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Humafactor IX	Kedrion	
☐	Immunine	Baxalta (Baxter Bioscience)	

☐	MonoFIX-VF	CSL Bioplasma	
☐	Mononine	CSL Behring	
☐	Nanofix	Octapharma	
☐	Nanotiv	Octapharma	
☐	Nonafact	Sanquin	
☐	Novact M	Kaketsuken	
☐	Octafix	Octapharma	
☐	Octanine F	Octapharma	
☐	Replenine – VF	BioProducts Lab.	
☐	Rixubis	Baxalta (Baxter Bioscience)	
☐	Other:		

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

22. Prothrombin Complex Concentrates used in 2016

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

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

23. Other Products used in 2016

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

Used	Brand Name	Manufacturer	Price per IU
☐	Aryoseven	Aryogen	

☐	Byclot (1.5mg)	Kaketusken	
☐	Ceprotin	Baxalta (Baxter Bioscience)	
☐	Clottafact Wilstart	LFB	
☐	Clottagen (fibrinogen)	LFB	
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
☐	FACTEUR VII	LFB	
☐	Factor VII	Baxalta (Baxter Bioscience)	
☐	Factor VII	Bio Products	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxalta (Baxter Bioscience)	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
☐	HEMOLEVEN (Factor XI)	LFB	
☐	Kovaltry	Bayer	
☐	NovoSeven (=Niastase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
☐	Riastap	CSL Behring	
☐	Tretten rXIII	NovoNordisk	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Other:		

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

Please return to:

Email: globalsurvey@wfh.org
Fax: 514-875-8916
Address: **World Federation of Hemophilia**
1425 René Lévesque Boulevard West, suite 1010
Montréal, Québec, H3G 1T7
Canada

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

Comments:

Annual Global Survey **2016**

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.

Notes

Notes

WFH

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