

# WORLD FEDERATION OF HEMOPHILIA REPORT ON THE



## ANNUAL GLOBAL SURVEY 2017



**WFH**

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

October 2018

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All data are provisional.

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# INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2017

The Report on the Annual Global Survey 2017 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 2017 data can be found on the website at: [www.wfh.org/en/data-collection](http://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 human immunodeficiency virus (HIV) and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to NMOs 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 2017 survey is the nineteenth WFH survey. 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 315,000 PWH, VWD and other bleeding disorders in 116 countries. This report also uses data from 2016 for reporting the number of patients identified. Not all members are able to report every year, therefore if a country reported last year and not this year, 2016 data was used.

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 population statistics (Table 6) 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 (Figure A) contains historical data from the Annual Global Survey. This graph was created using aggregate numbers to demonstrate the increase 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, the analysis was done using only data from countries that responded in 2017, 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 PWH 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 2017 only. It includes only those countries where the NMO provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2017.

Some countries are not reporting for the whole country and in some cases the numbers reported may be based on an estimate or from one region or certain treatment centres only. The amounts reported may only be factor bought through government and not through other sources. Not all NMOs 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 280,000 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 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) Methods of data collection and the state of registries can vary. 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 and it can be 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 HCV is not the same around the world. In some countries infection rates may be lower, while other countries may have had better treatment for infected people with hemophilia.

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

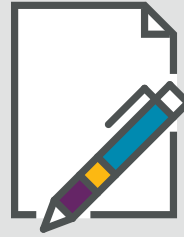
**Chair:** Jeff Stonebraker  
**Members:** Vanessa Byams  
Hervé Chambost  
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Alfonso Iorio (Past Chair)  
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**Annual Global Survey Reviewers:**  
Paula Bolton-Maggs (Past Chair)  
Randall Curtis  
Suely Rezende  
Mike Soucie  
Alok Srivastava

# KEY NUMBERS

From the 2017 Report on the Annual Global Survey

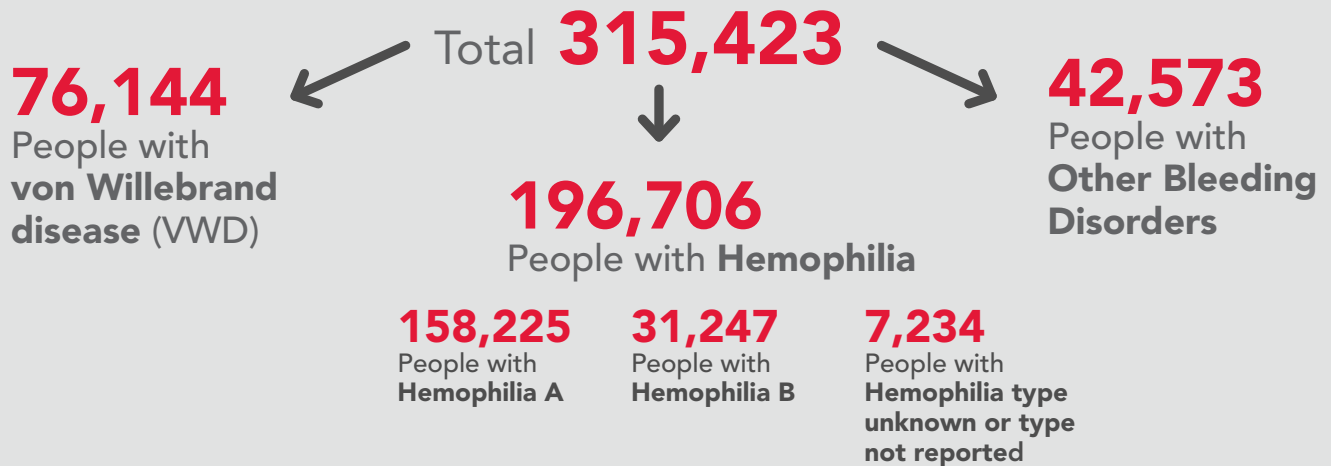
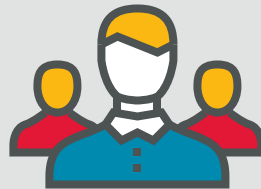
116 Countries Represented



75%

Response Rate from WFH National Member Organizations (105/140)

6.6% increase in number of people with bleeding disorders identified from 2016–2017



Factor VIII Usage per capita

**1.09 IU**

(0.08 – 4.79)

Median (IQR)

(93 countries, 68% of the world population)



Factor IX Usage per capita

**0.17 IU**

(0.01-0.60)

Median (IQR)

(89 countries, 67% of the world population)



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# REPORT ON THE ANNUAL GLOBAL SURVEY 2017 SUMMARY DEMOGRAPHICS

**Table 1. Demographics**

|   |         |
|---|---------|
| Number of countries in this survey                                    | 116     |
| World population covered by countries in this survey report           | 91%     |
| Number of people identified with hemophilia                           | 196,706 |
| Number of people identified with VWD                                  | 76,144  |
| Number of people identified with other bleeding disorders             | 42,573  |
| Total number of people with bleeding disorders identified             | 315,423 |
| Number of people with hemophilia A                                    | 158,225 |
| Number of people with hemophilia B                                    | 31,247  |
| Number of people with hemophilia type unknown or type not reported    | 7,234   |
| Number of hemophilia A patients with clinically identified inhibitors | 5,948   |
| Number of hemophilia B patients with clinically identified inhibitors | 342     |

*These numbers represent the total number of people identified, including those newly identified in 2017. It is possible that some countries included in this report have not surveyed their entire population.*

*PLEASE NOTE: The Report on the Annual Global Survey 2017 also uses data from the year 2016. For the 2017 survey report, 105 countries submitted data for 2017. Historical data from 2016 was used for 11 countries. 2016 survey data is 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 efforts to improve the overall quality of data we report each year.*

## Table 2. Factor VIII usage 2017

|  | FACTOR USAGE           | NUMBER OF COUNTRIES |
|--|------------------------|---------------------|
| Mean global per capita factor VIII usage                             | 2.61 IU                | 93                  |
| Median global per capita factor VIII usage                           | 1.09 IU                | 93                  |
| Interquartile range (IQR) global per capita factor VIII usage        | 4.71 IU (0.08 to 4.79) | 93                  |
| Total reported annual global consumption of factor VIII concentrates | 11,121,470,678 IU      | 93                  |

## Table 3. Factor IX usage 2017

|  | FACTOR USAGE           | NUMBER OF COUNTRIES |
|--|------------------------|---------------------|
| Mean global per capita factor IX usage                             | 0.40 IU                | 89                  |
| Median global per capita factor IX usage                           | 0.17 IU                | 89                  |
| Interquartile range (IQR) global per capita factor IX usage        | 0.58 IU (0.01 to 0.60) | 89                  |
| Total reported annual global consumption of factor IX concentrates | 1,674,911,682 IU       | 89                  |

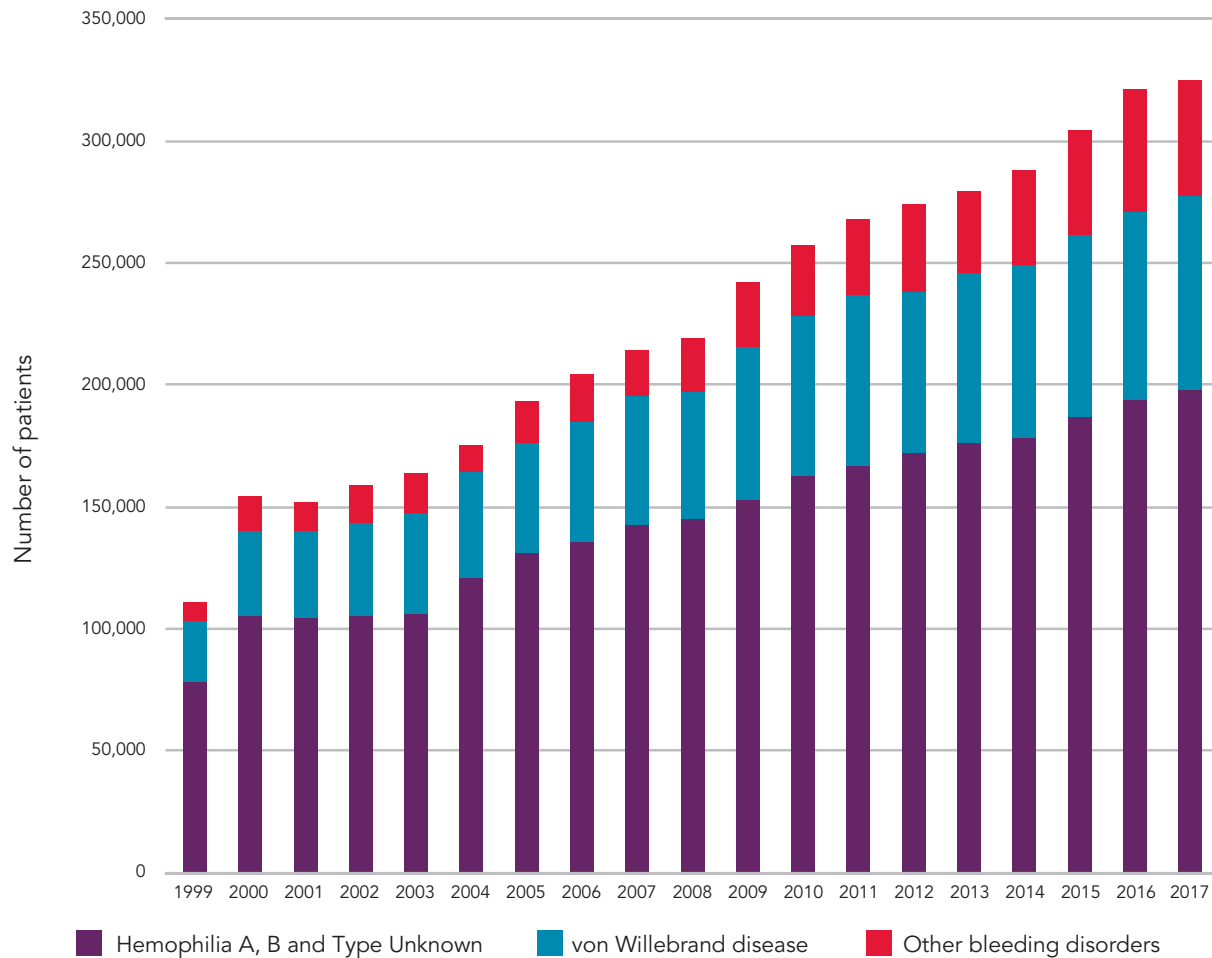
The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using 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 the mean, median and IQR of per capita factor usage for the countries that reported in both the 2016 and 2017 surveys.

**Table 4. Factor use in 2016 and 2017**

|   | 2016                      | 2017                      | COUNTRIES REPORTING |
|---|---------------------------|---------------------------|---------------------|
| Mean global per capita factor VIII usage                      | 2.34 IU                   | 2.62 IU                   | 77                  |
| Median global per capita factor VIII usage                    | 0.53 IU                   | 1.09 IU                   | 77                  |
| Interquartile range (IQR) global per capita factor VIII usage | 4.46 IU<br>(0.06 to 4.53) | 4.78 IU<br>(0.07 to 4.85) | 77                  |
| Mean global per capita factor IX usage                        | 0.38 IU                   | 0.41 IU                   | 73                  |
| Median global per capita factor IX usage                      | 0.10 IU                   | 0.18 IU                   | 73                  |
| Interquartile range (IQR) global per capita factor IX usage   | 0.59 IU<br>(0.01 to 0.60) | 0.69 IU<br>(0.01 to 0.69) | 73                  |

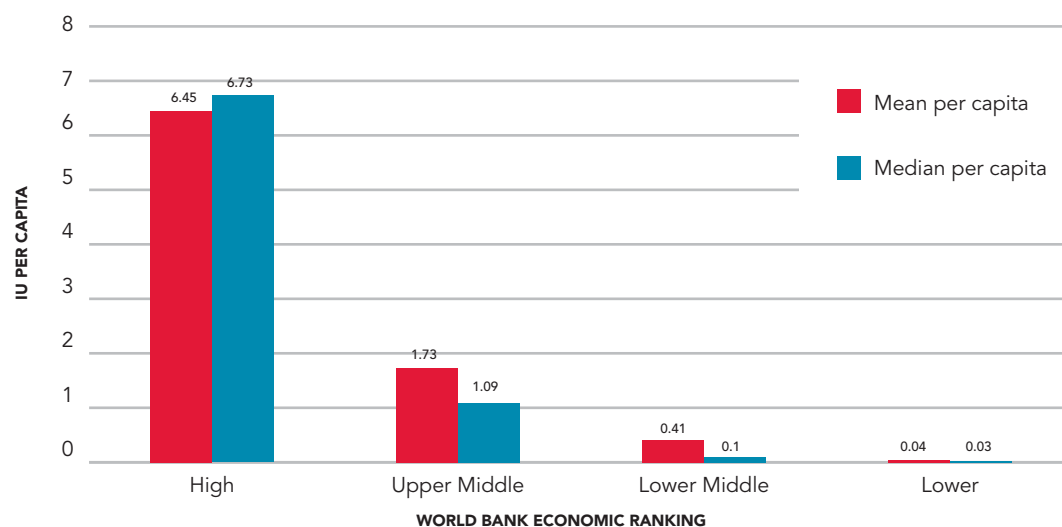
Figure A. Identified patients over time – all bleeding disorders



This graph was created using aggregate numbers to demonstrate the increase in patients identified over time. This graph contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next. **For each year in Figure A only, historical data for up to 3 years is used.** For the number of patients identified this year, we used data from 2017 for 106 countries, 2016 numbers for 11 countries and 2015 numbers for 6 countries. This reflects an estimate of the total number of identified patients with inherited bleeding disorders.

## Figure B1. Mean and median global factor VIII use per capita

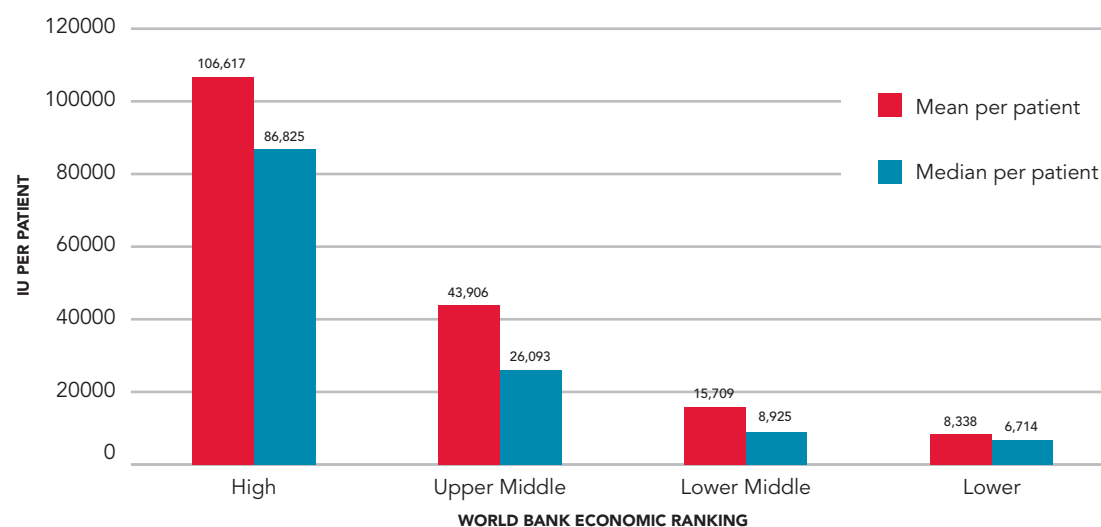
(Data from 93 countries.)



Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more.

## Figure B2. Mean and median global factor VIII use per patient

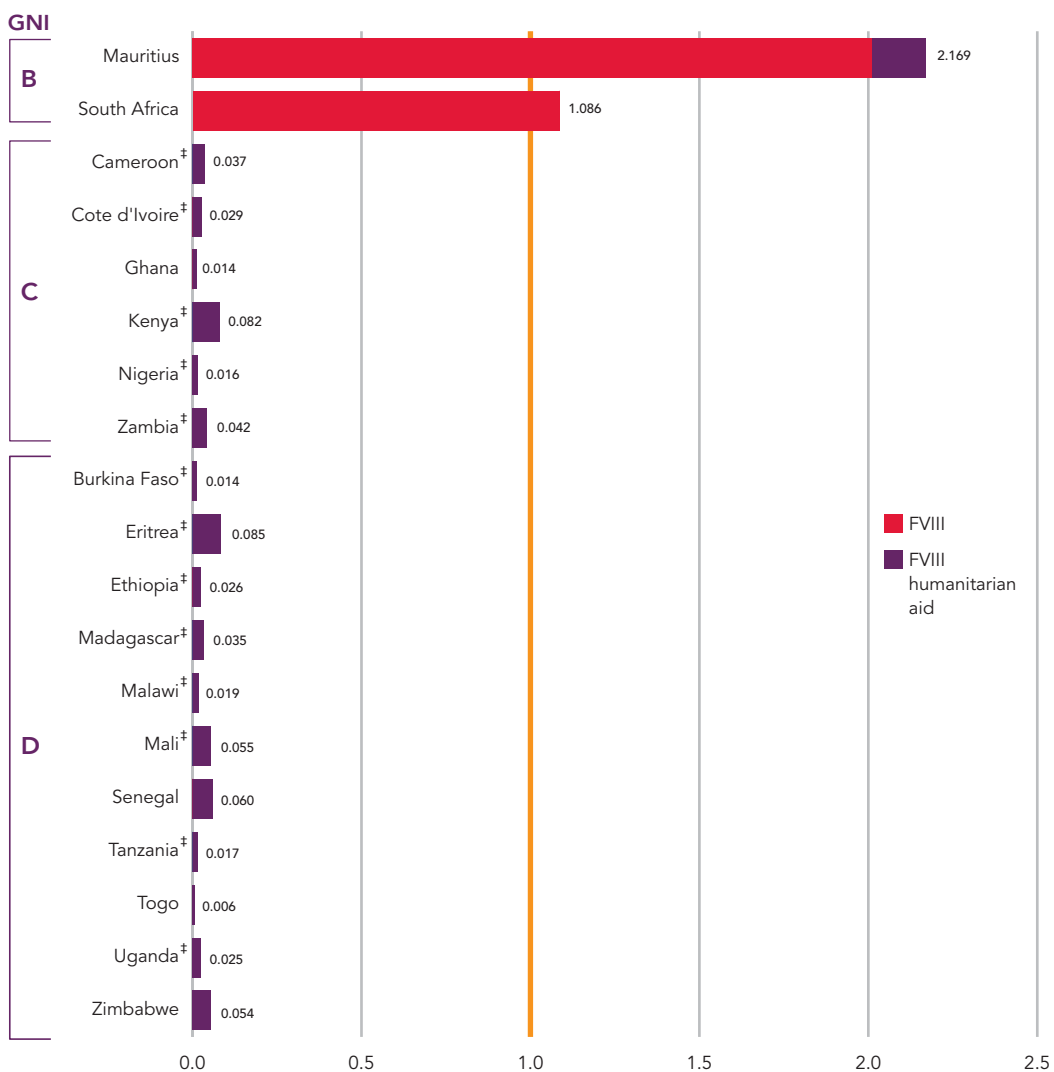
(Data from 92 countries.)



Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 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 2017 – regional and GNI comparisons of IU/total population: Africa

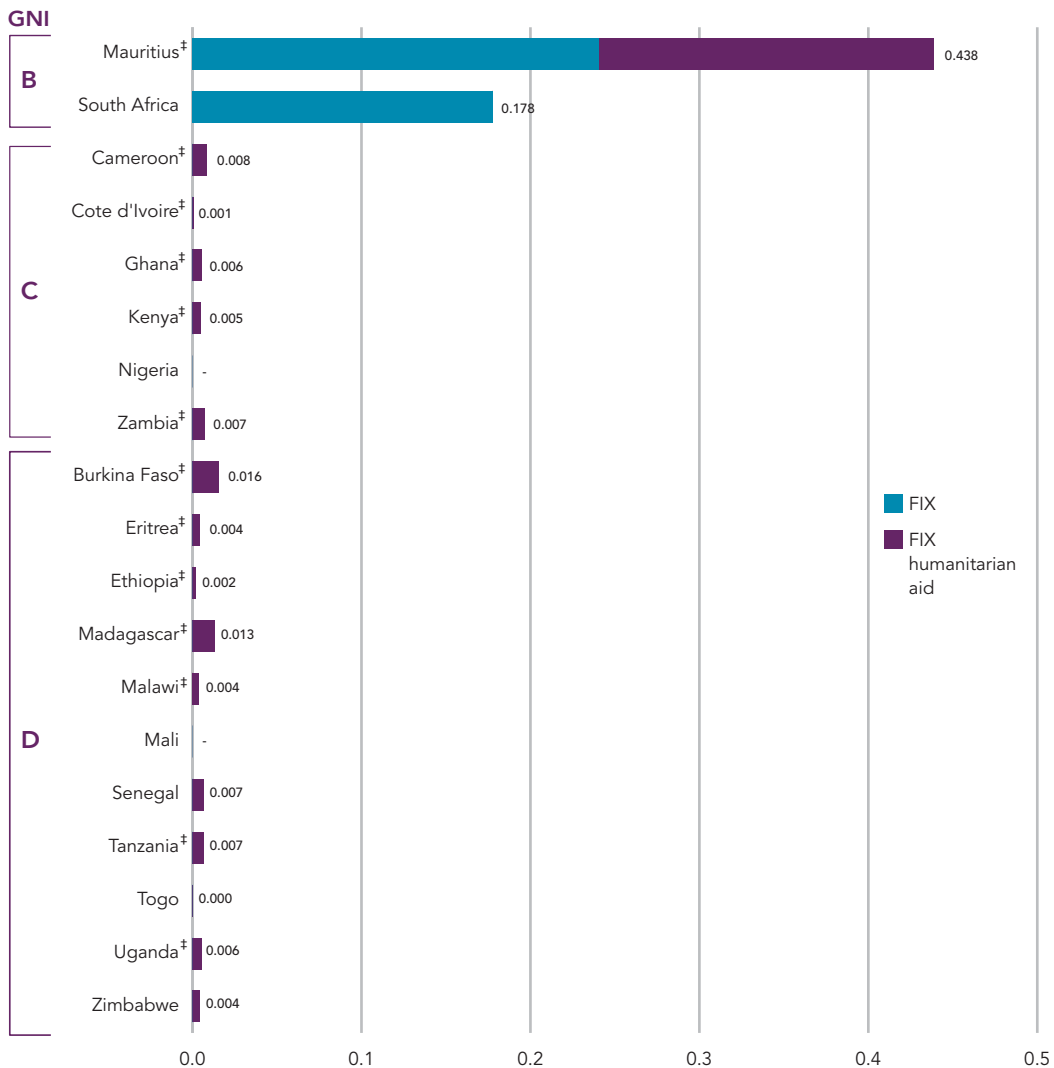


Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$996–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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 provided product use data in the 2017 questionnaire are included in Figure C graphs.

<sup>‡</sup> Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C1b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: Africa

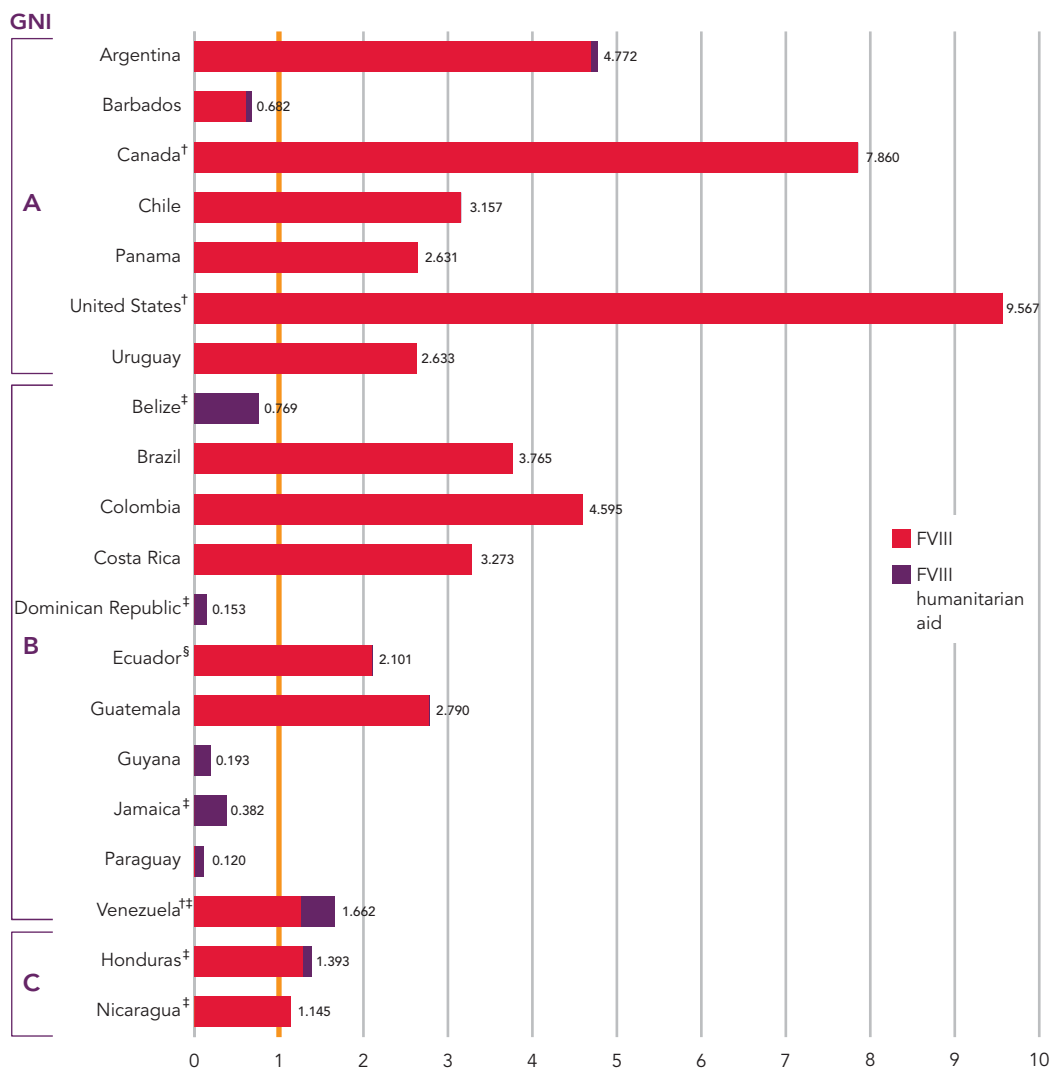


Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. Only countries that provided product use data in the 2017 questionnaire are included in Figure C graphs.

<sup>‡</sup> Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C2a. Mean per capita factor VIII use in 2017 – regional and GNI comparisons of IU/total population: Americas



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$99–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

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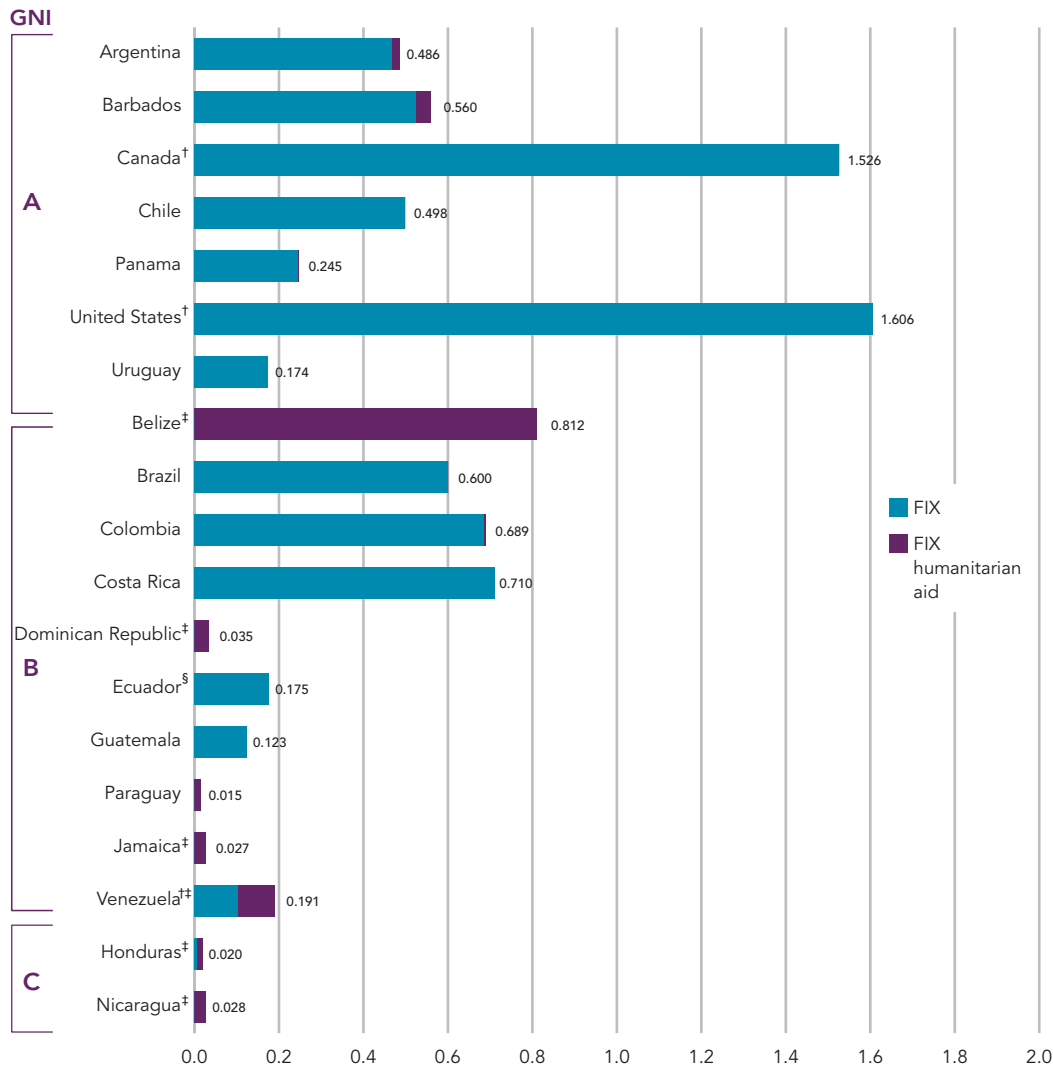
†Countries that have purchased extended half-life products

‡Countries that have received extended half-life product donations from WFH humanitarian aid

§ Data added/modified after final report; amounts not included in totals



Figure C2b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: Americas



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

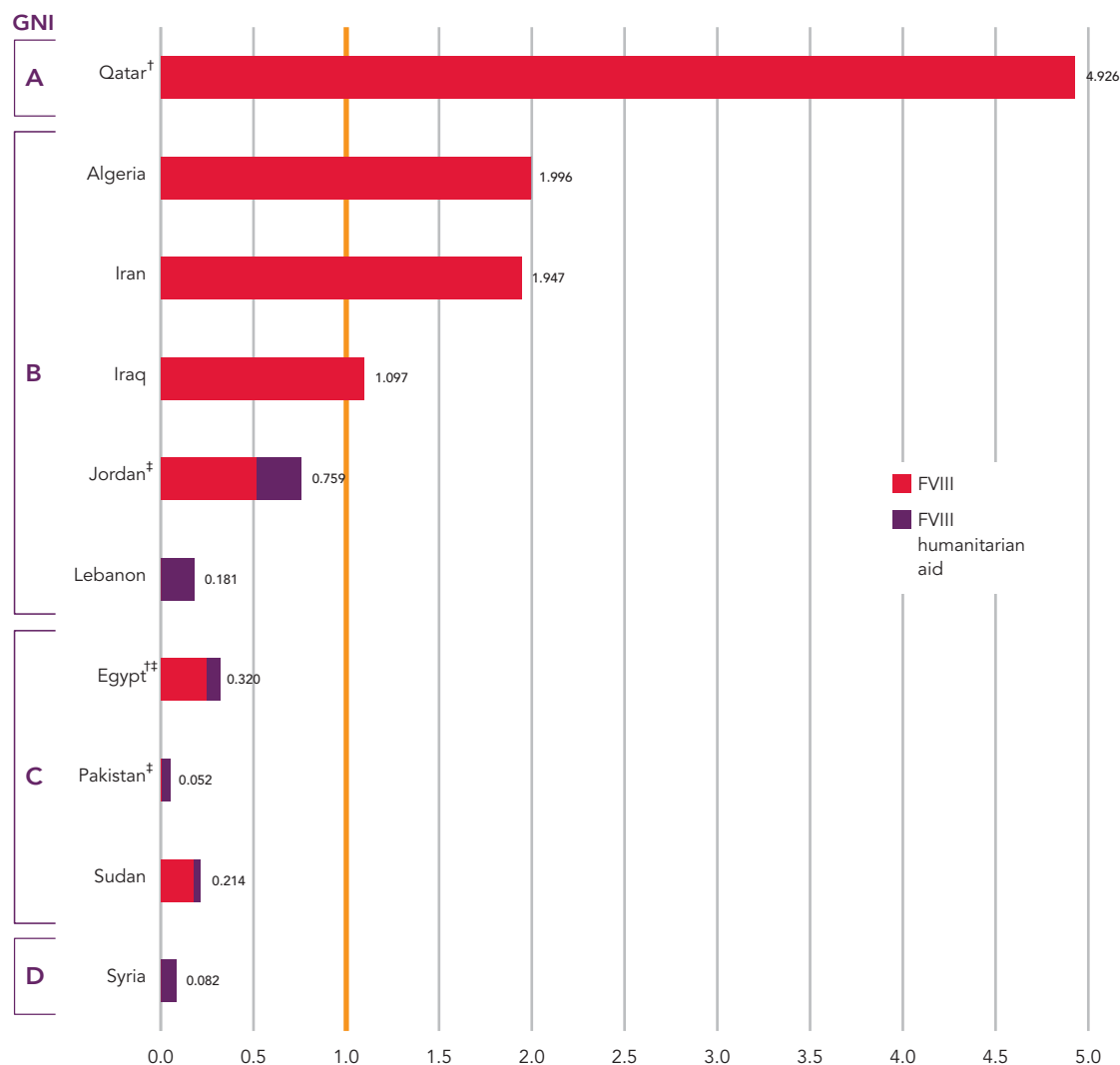
PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. Only countries that provided product use data in the 2017 questionnaire are included in Figure C graphs.

†Countries that have purchased extended half-life products

††Countries that have received extended half-life product donations from WFH humanitarian aid

§ Data added/modified after final report; amounts not included in totals

Figure C3a. Mean per capita factor VIII use in 2017 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



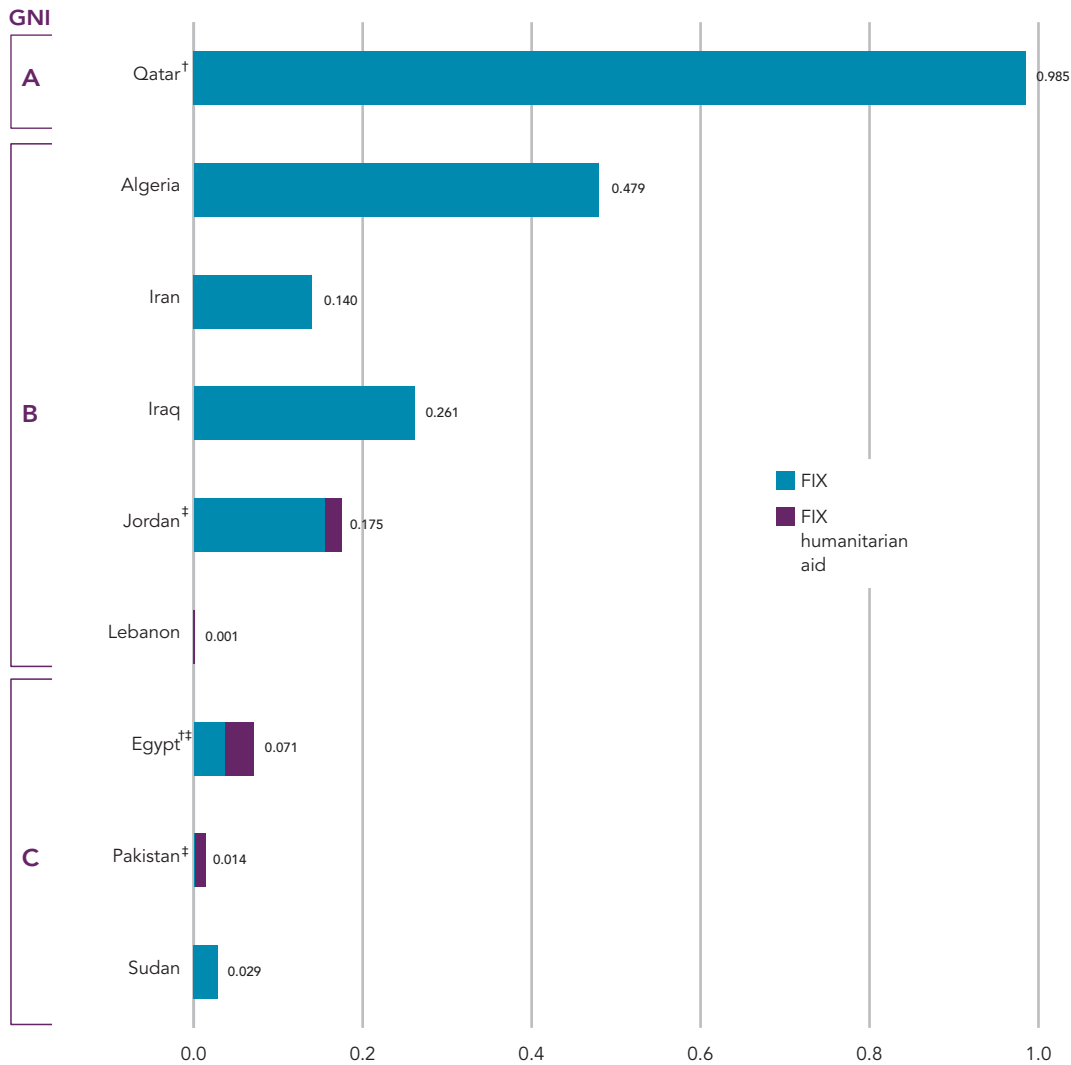
Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$996–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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 provided product use data in the 2017 questionnaire are included in Figure C graphs.

†Countries that have purchased extended half-life products

††Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C3b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



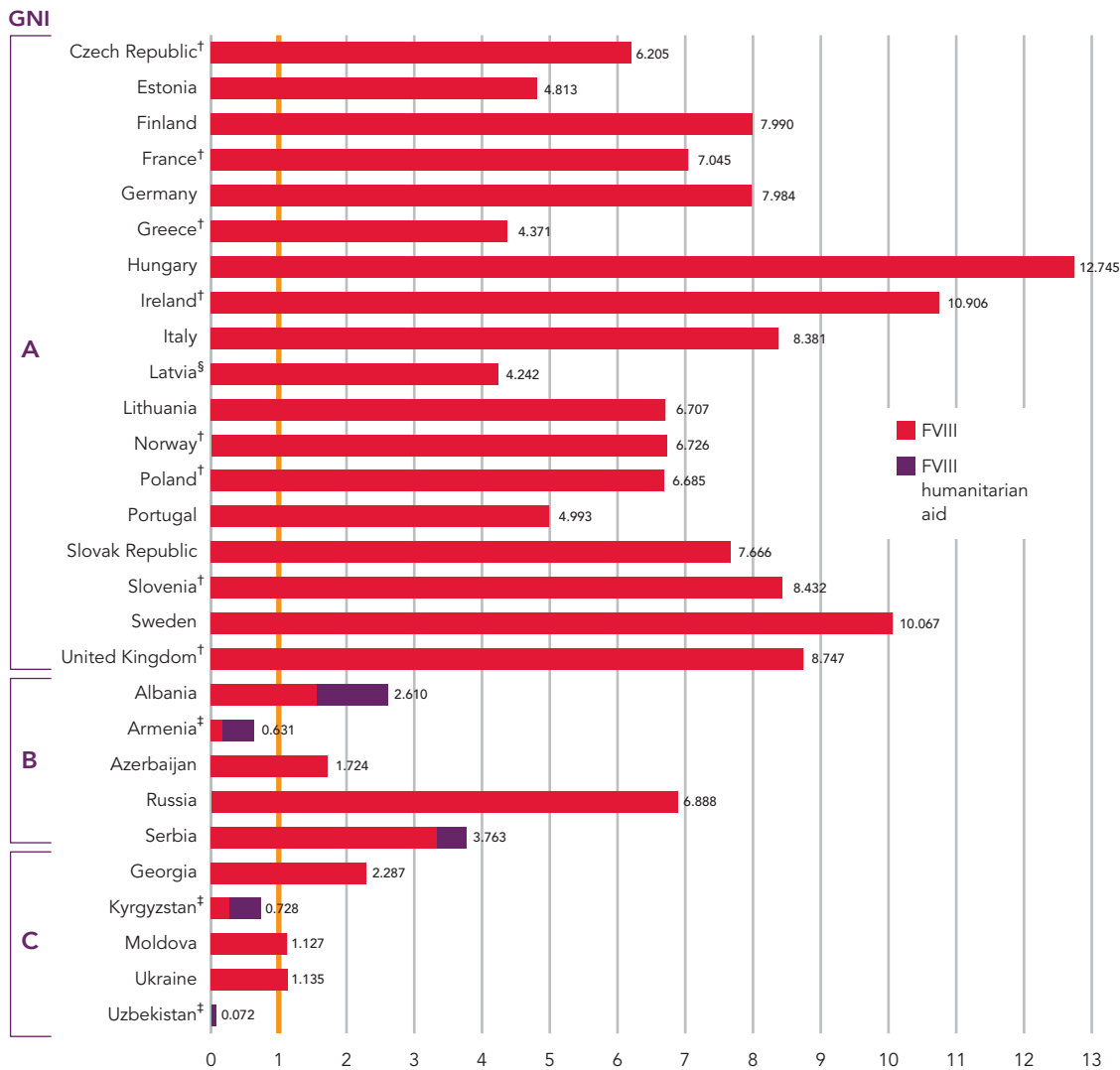
Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. Only countries that provided product use data in the 2017 questionnaire are included in Figure C graphs.

†Countries that have purchased extended half-life products

‡Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C4a. Mean per capita factor VIII use in 2017 – regional and GNI comparisons of IU/total population: Europe



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$996–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

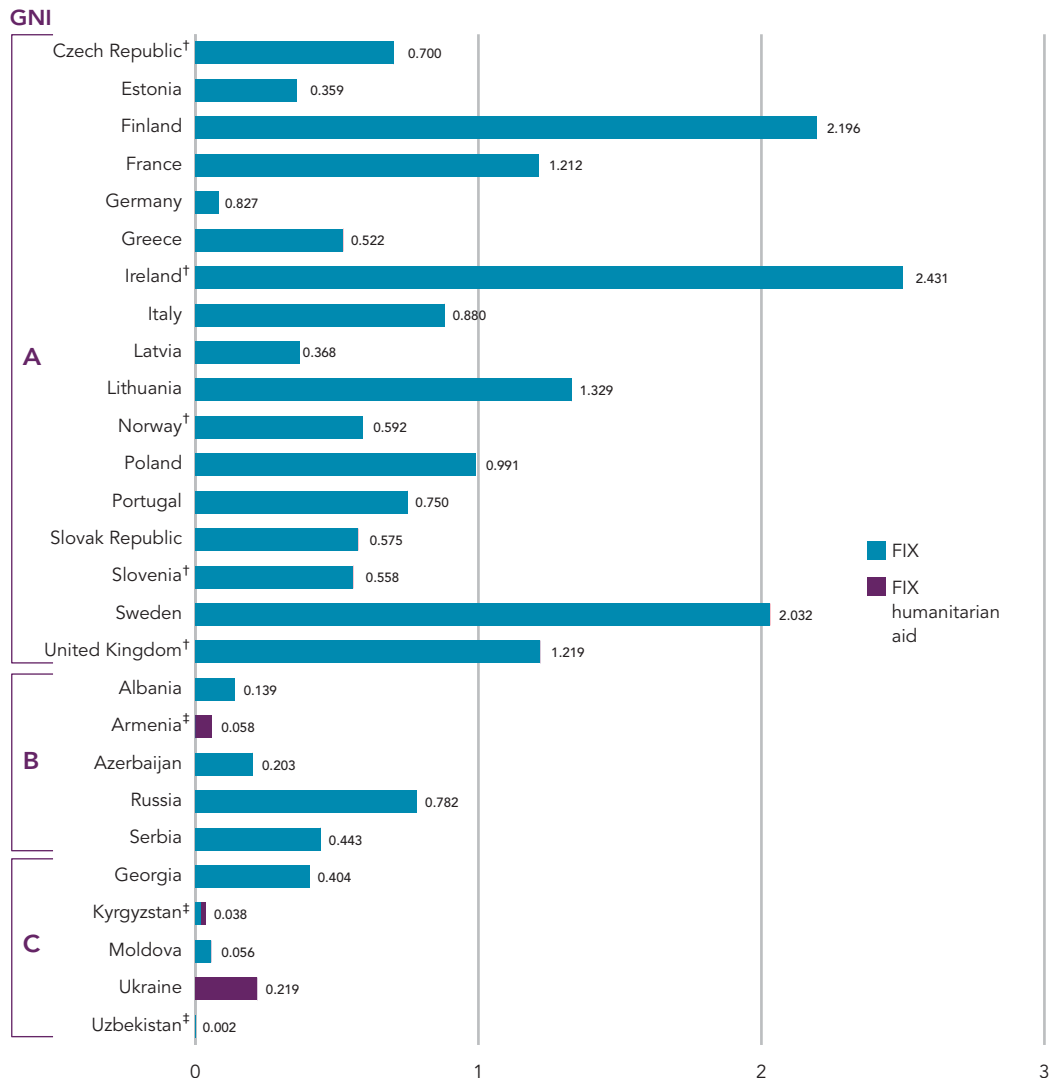
PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries 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 provided product use data in the 2017 questionnaire are included in Figure C graphs.

†Countries that have purchased extended half-life products

‡Countries that have received extended half-life product donations from WFH humanitarian aid

§ Data added/modified after final report; amounts not included in totals

Figure C4b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: Europe



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

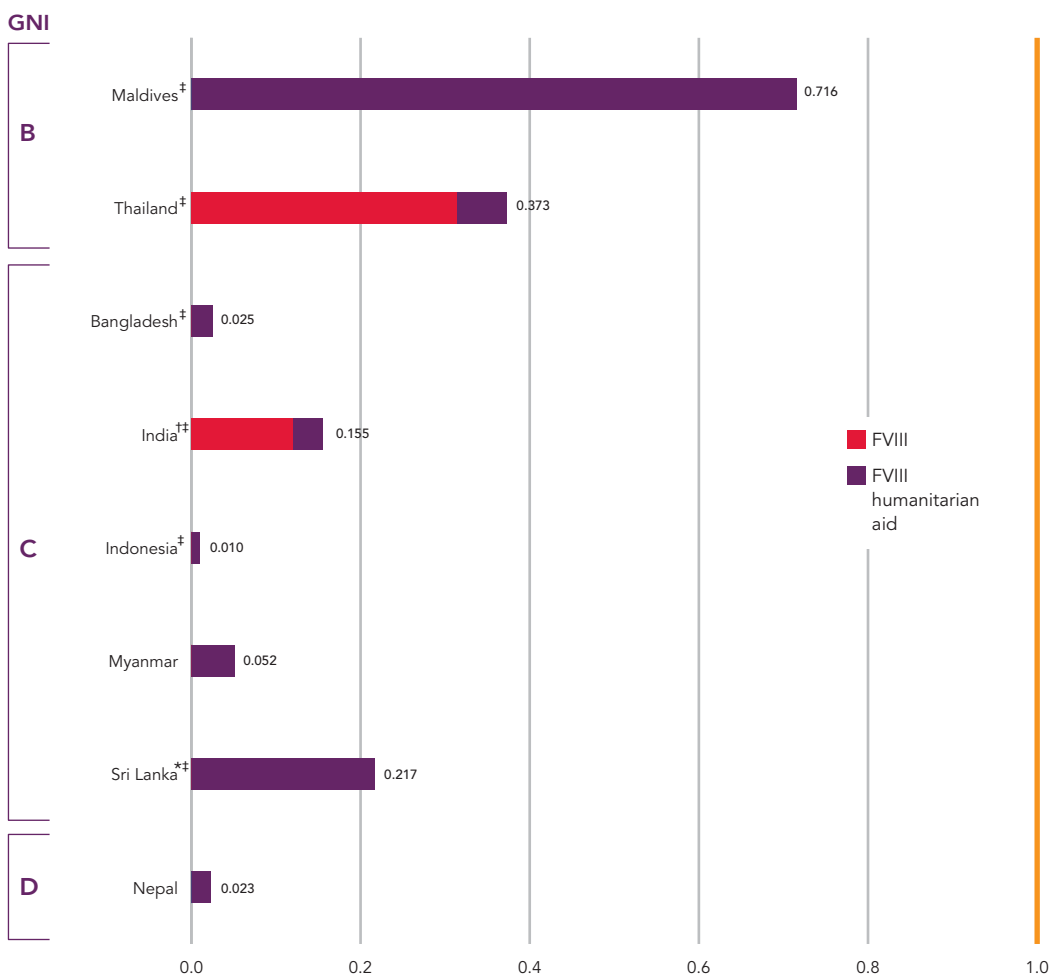
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†Countries that have purchased extended half-life products

‡Countries that have received extended half-life product donations from WFH humanitarian aid

§ Data added/modified after final report; amounts not included in totals

Figure C5a. Mean per capita factor VIII use in 2017 – regional and GNI comparisons of IU/total population: South-East Asia



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$996–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more.

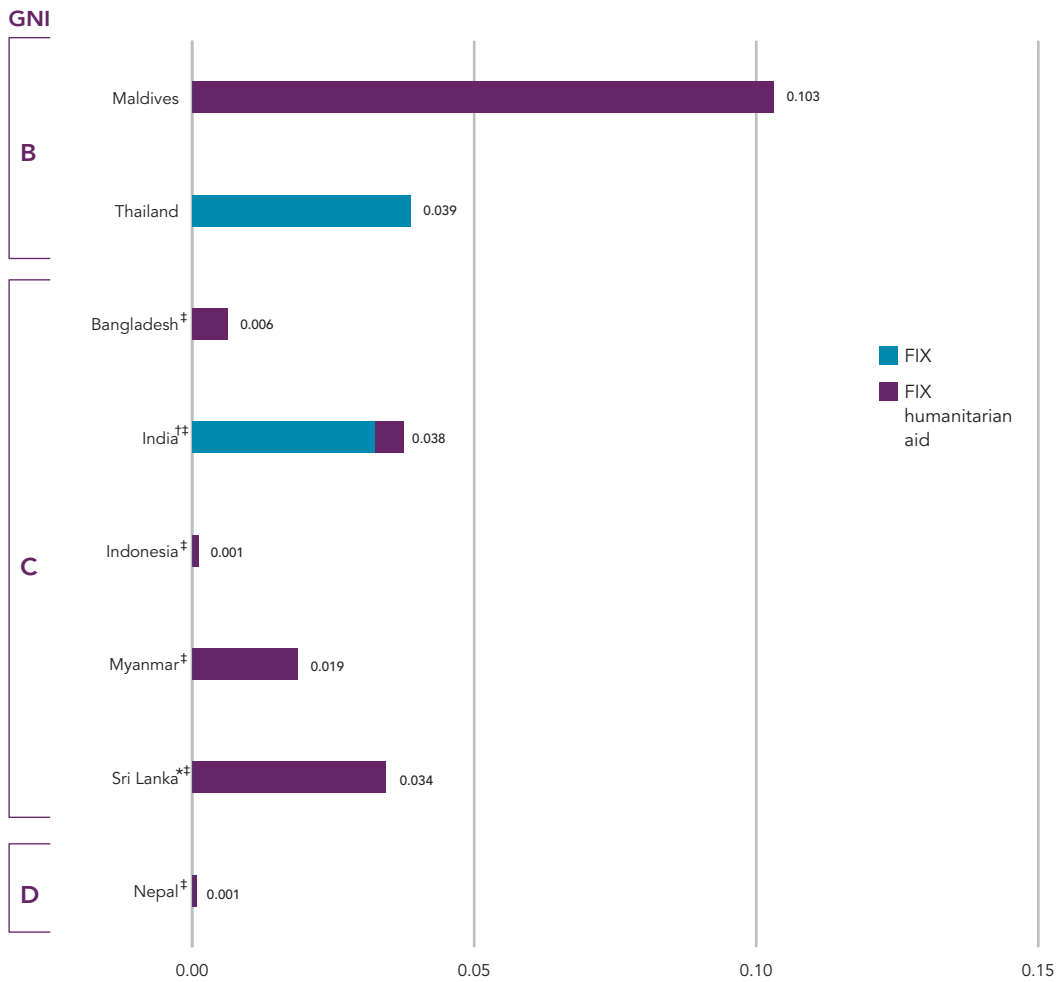
PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries 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 provided product use data in the 2017 questionnaire are included in Figure C graphs.

\*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.

†Countries that have purchased extended half-life products

†Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C5b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: South-East Asia



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

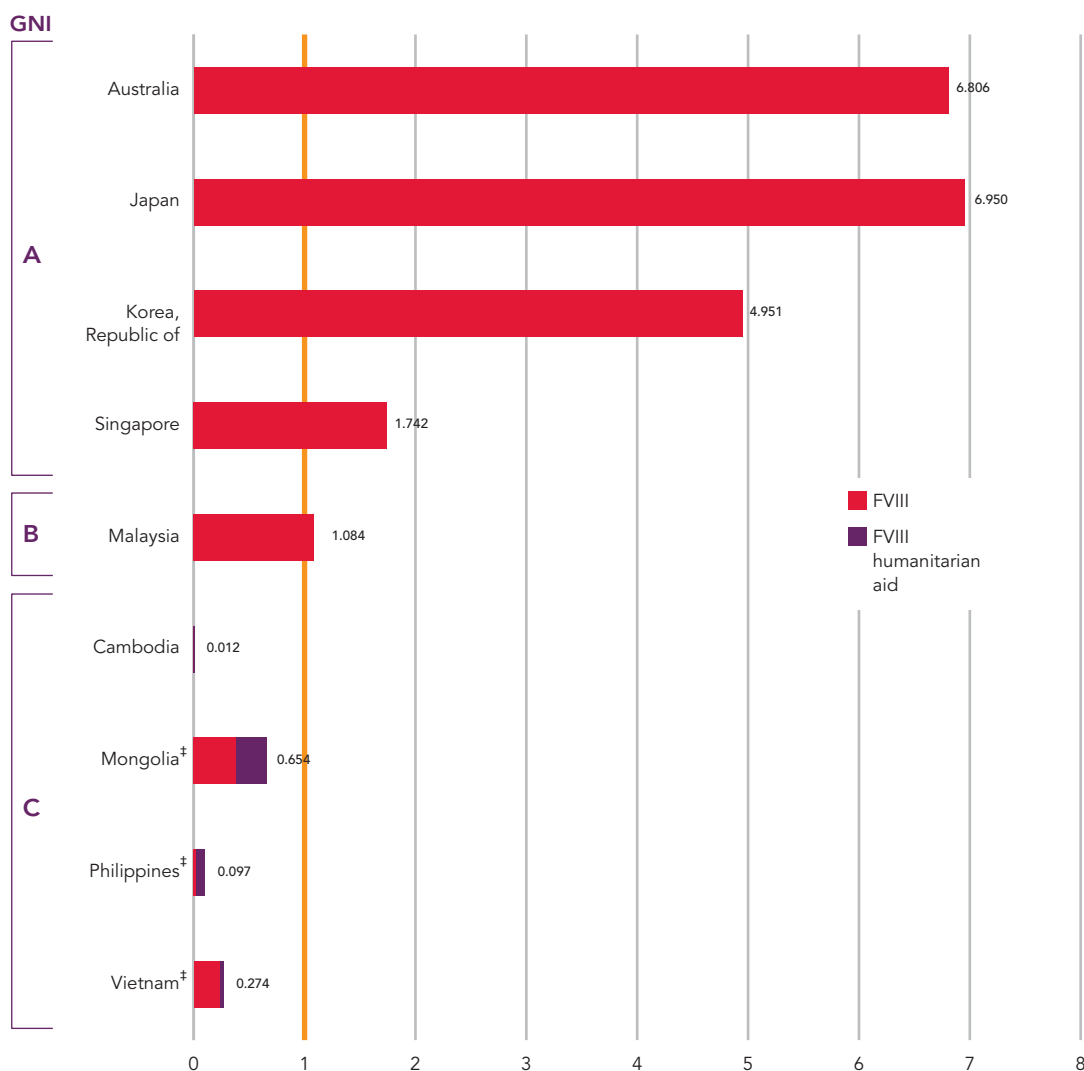
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‡Countries that have received extended half-life product donations from WFH humanitarian aid

Figure C6a. Mean per capita factor VIII use in 2017 – regional and GNI comparisons of IU/total population: Western Pacific



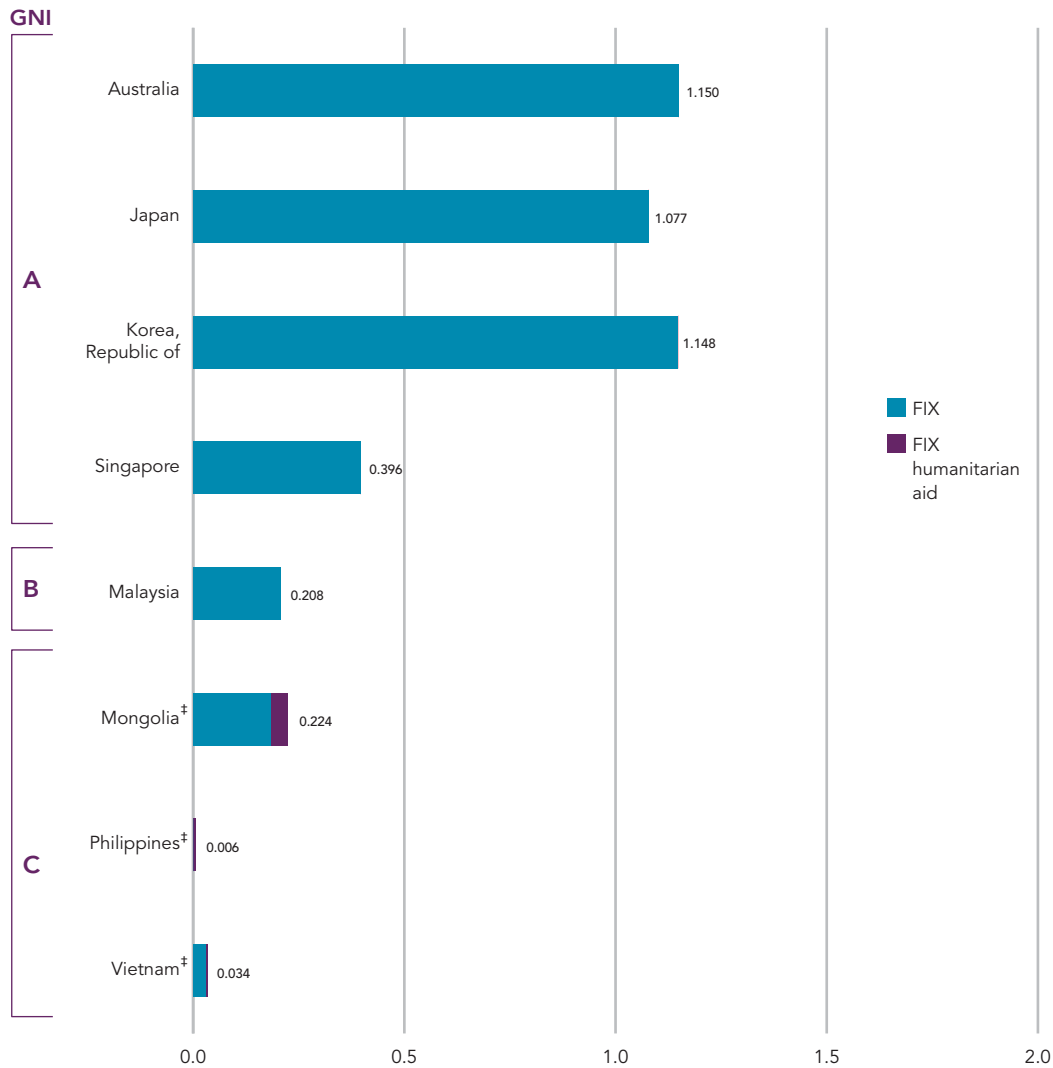
Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0–\$995; C lower middle income, \$996–\$3,895; B upper middle income, \$3,896–\$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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 provided product use data in the 2017 questionnaire are included in Figure C graphs.

<sup>†</sup>Countries that have received extended half-life product donations from WFH humanitarian aid



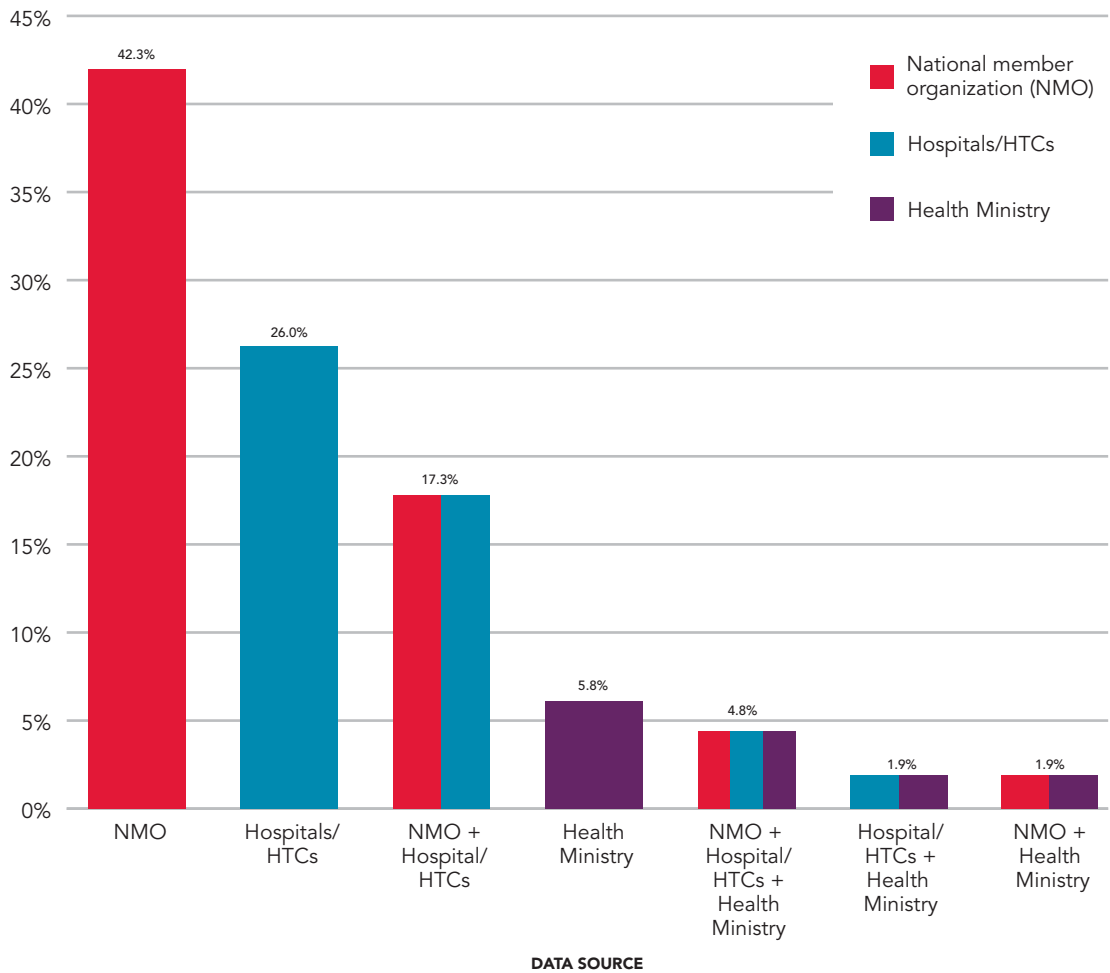
Figure C6b. Mean per capita factor IX use in 2017 – regional and GNI comparisons of IU/total population: Western Pacific



Economic category based on The World Bank Group 2017 rankings for “Gross national income (GNI) per capita, Atlas method (current US\$)”. GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more. Regions based on WHO regions.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure C. Only countries that provided product use data in the 2017 questionnaire are included in Figure C graphs.

†Countries that have received extended half-life product donations from WFH humanitarian aid



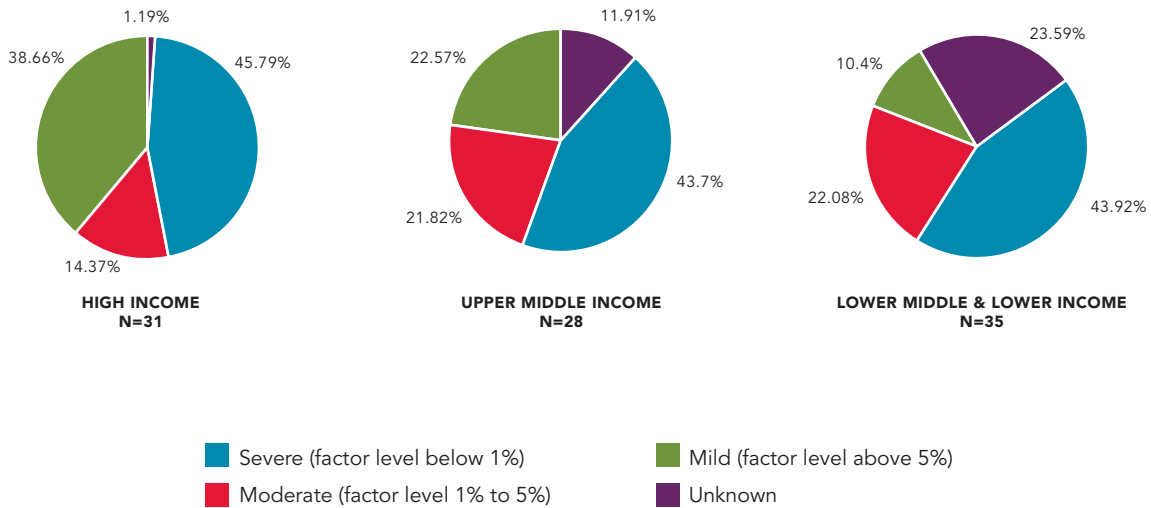
**Figure D. Data source**

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

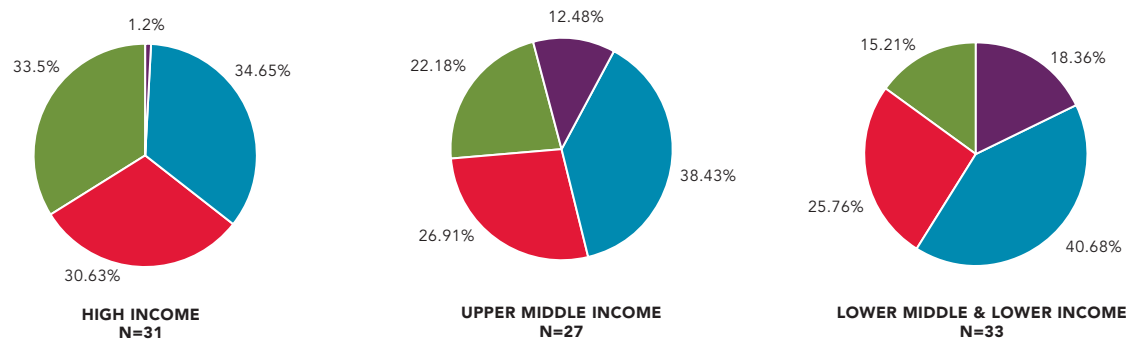
## Figure E1. Severity of hemophilia in males by GNI

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

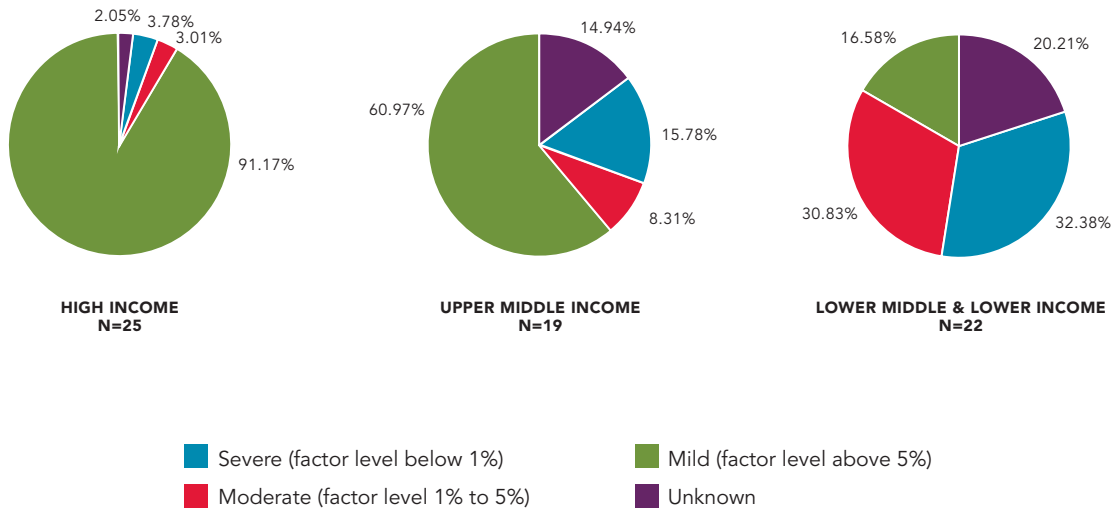


Economic category based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more.

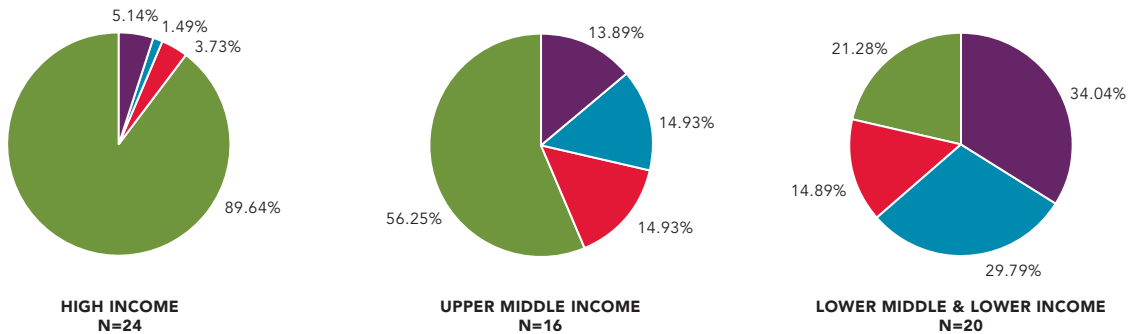
## Figure E2. Severity of hemophilia in females –by GNI

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 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US\$)". GNI in US dollars: D lower income, \$0-\$995; C lower middle income, \$996 - \$3,895; B upper middle income, \$3,896 - \$12,055; and A high income, \$12,056 or more.

## Table 5. Countries included in the Report on the Annual Global Survey 2017

Please note: the year indicates the year the data was submitted. Not all of our members are able to submit data every year. For the 2017 survey report, 105 countries submitted data for 2017. Countries in **BOLD** reported data for 2017.

2016 data was used for 11 countries to report the number of patients identified. All other numbers in this report are from 2017 only.

|                           |      |                           |      |                    |      |                        |      |
|---------------------------|------|---------------------------|------|--------------------|------|------------------------|------|
| Afghanistan               | 2016 | <b>Ecuador</b>            | 2017 | Latvia             | 2016 | <b>Qatar</b>           | 2017 |
| <b>Albania</b>            | 2017 | <b>Egypt</b>              | 2017 | <b>Lebanon</b>     | 2017 | Romania                | 2016 |
| <b>Algeria</b>            | 2017 | <b>Eritrea</b>            | 2017 | <b>Lesotho</b>     | 2017 | <b>Russia</b>          | 2017 |
| <b>Argentina</b>          | 2017 | <b>Estonia</b>            | 2017 | <b>Lithuania</b>   | 2017 | Saudi Arabia           | 2016 |
| <b>Armenia</b>            | 2017 | <b>Ethiopia</b>           | 2017 | <b>Madagascar</b>  | 2017 | <b>Senegal</b>         | 2017 |
| <b>Australia</b>          | 2017 | <b>Finland</b>            | 2017 | <b>Malawi</b>      | 2017 | <b>Serbia</b>          | 2017 |
| <b>Austria</b>            | 2017 | <b>France</b>             | 2017 | <b>Malaysia</b>    | 2017 | <b>Singapore</b>       | 2017 |
| <b>Azerbaijan</b>         | 2017 | <b>Georgia</b>            | 2017 | <b>Maldives</b>    | 2017 | <b>Slovak Republic</b> | 2017 |
| <b>Bangladesh</b>         | 2017 | <b>Germany</b>            | 2017 | <b>Mali</b>        | 2017 | <b>Slovenia</b>        | 2017 |
| <b>Barbados</b>           | 2017 | <b>Ghana</b>              | 2017 | <b>Mauritius</b>   | 2017 | <b>South Africa</b>    | 2017 |
| <b>Belarus</b>            | 2017 | <b>Greece</b>             | 2017 | <b>Mexico</b>      | 2017 | <b>Sri Lanka</b>       | 2017 |
| <b>Belgium</b>            | 2017 | <b>Guatemala</b>          | 2017 | <b>Moldova</b>     | 2017 | <b>Sudan</b>           | 2017 |
| <b>Belize</b>             | 2017 | <b>Guyana</b>             | 2017 | <b>Mongolia</b>    | 2017 | <b>Sweden</b>          | 2017 |
| Bolivia                   | 2016 | <b>Honduras</b>           | 2017 | Montenegro         | 2016 | <b>Switzerland</b>     | 2017 |
| <b>Botswana</b>           | 2017 | <b>Hong Kong (China)</b>  | 2017 | Morocco            | 2016 | <b>Syria</b>           | 2017 |
| <b>Brazil</b>             | 2017 | <b>Hungary</b>            | 2017 | <b>Mozambique</b>  | 2017 | <b>Tanzania</b>        | 2017 |
| <b>Burkina Faso</b>       | 2017 | <b>India</b>              | 2017 | <b>Myanmar</b>     | 2017 | <b>Thailand</b>        | 2017 |
| <b>Cambodia</b>           | 2017 | <b>Indonesia</b>          | 2017 | <b>Nepal</b>       | 2017 | <b>Togo</b>            | 2017 |
| <b>Cameroon</b>           | 2017 | <b>Iran</b>               | 2017 | <b>New Zealand</b> | 2017 | <b>Tunisia</b>         | 2017 |
| <b>Canada</b>             | 2017 | <b>Iraq</b>               | 2017 | <b>Nicaragua</b>   | 2017 | <b>Uganda</b>          | 2017 |
| <b>Chile</b>              | 2017 | <b>Ireland</b>            | 2017 | <b>Nigeria</b>     | 2017 | <b>Ukraine</b>         | 2017 |
| China                     | 2016 | <b>Israel</b>             | 2017 | <b>Norway</b>      | 2017 | <b>United Kingdom</b>  | 2017 |
| <b>Colombia</b>           | 2017 | <b>Italy</b>              | 2017 | Oman               | 2016 | <b>United States</b>   | 2017 |
| <b>Costa Rica</b>         | 2017 | <b>Jamaica</b>            | 2017 | <b>Pakistan</b>    | 2017 | <b>Uruguay</b>         | 2017 |
| <b>Cote d'Ivoire</b>      | 2017 | <b>Japan</b>              | 2017 | <b>Panama</b>      | 2017 | <b>Uzbekistan</b>      | 2017 |
| Cuba                      | 2016 | <b>Jordan</b>             | 2017 | <b>Paraguay</b>    | 2017 | <b>Venezuela</b>       | 2017 |
| <b>Czech Republic</b>     | 2017 | <b>Kenya</b>              | 2017 | <b>Philippines</b> | 2017 | <b>Vietnam</b>         | 2017 |
| Denmark                   | 2016 | <b>Korea, Republic of</b> | 2017 | <b>Poland</b>      | 2017 | <b>Zambia</b>          | 2017 |
| <b>Dominican Republic</b> | 2017 | <b>Kyrgyzstan</b>         | 2017 | <b>Portugal</b>    | 2017 | <b>Zimbabwe</b>        | 2017 |

## 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 2017. 2016 survey data are only used for reporting the number of patients identified for countries that reported population statistics in 2016 but not in 2017 – all other numbers in this report are from 2017 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                            |
| <b>Albania</b>      | 2,873,457     | 218                    | 6                                  | 8                                    |
| <b>Algeria</b>      | 41,318,142    | 2,245                  | 320                                | 568                                  |
| <b>Argentina</b>    | 44,271,041    | 2,674                  | 398                                | 10                                   |
| <b>Armenia</b>      | 2,930,450     | 201                    | 15                                 | 46                                   |
| <b>Australia</b>    | 24,598,933    | 2,635                  | 2,139                              | 785                                  |
| <b>Austria</b>      | 8,809,212     | 798                    | Not Known                          | Not Known                            |
| <b>Azerbaijan</b>   | 9,862,429     | 1,304                  | 205                                | 96                                   |
| <b>Bangladesh</b>   | 164,669,751   | 1,249                  | 2                                  | 3                                    |
| <b>Barbados</b>     | 285,719       | 33                     | 2                                  | 2                                    |
| <b>Belarus</b>      | 9,507,875     | 646                    | 196                                | 59                                   |
| <b>Belgium</b>      | 11,372,068    | 1,239                  | 1,972                              | 465                                  |
| <b>Belize</b>       | 374,681       | 18                     | Not Known                          | Not Known                            |
| Bolivia             | 10,887,882    | 200                    | 1                                  | Not Known                            |
| <b>Botswana</b>     | 2,291,661     | 43                     | 4                                  | Not Known                            |
| <b>Brazil</b>       | 209,288,278   | 12,432                 | 8,531                              | 3,243                                |
| <b>Burkina Faso</b> | 19,193,382    | 63                     | Not Known                          | Not Known                            |
| <b>Cambodia</b>     | 16,005,373    | 164                    | 4                                  | 6                                    |
| <b>Cameroon</b>     | 24,053,727    | 150                    | 3                                  | Not Known                            |
| <b>Canada</b>       | 36,708,083    | 4,023                  | 4,669                              | 1,341                                |
| <b>Chile</b>        | 18,054,726    | 1,700                  | 434                                | 774                                  |
| China               | 1,378,665,000 | 14,390                 | 72                                 | 90                                   |
| <b>Colombia</b>     | 49,065,615    | 2,773                  | 1,612                              | 297                                  |
| <b>Costa Rica</b>   | 4,905,769     | 216                    | 87                                 | 63                                   |

|                           | Population    | People with hemophilia | People with von Willebrand disease | People with other bleeding disorders |
|---------------------------|---------------|------------------------|------------------------------------|--------------------------------------|
| <b>Cote d'Ivoire</b>      | 24,294,750    | 94                     | 3                                  | 3                                    |
| Cuba                      | 11,475,982    | 470                    | 351                                | 3,220                                |
| <b>Czech Republic</b>     | 10,591,323    | 1,077                  | 837                                | 132                                  |
| Denmark                   | 5,731,118     | 523                    | 309                                | 145                                  |
| <b>Dominican Republic</b> | 10,766,998    | 374                    | 27                                 | 33                                   |
| <b>Ecuador</b>            | 16,624,858    | 854                    | 99                                 | 6                                    |
| <b>Egypt</b>              | 97,553,151    | 5,779                  | 562                                | 1,232                                |
| <b>Eritrea</b>            | 5,869,869     | 56                     | Not Known                          | Not Known                            |
| <b>Estonia</b>            | 1,315,480     | 111                    | 111                                | 101                                  |
| <b>Ethiopia</b>           | 104,957,438   | 301                    | 25                                 | 3                                    |
| <b>Finland</b>            | 5,511,303     | 247                    | 541                                | Not Known                            |
| <b>France</b>             | 67,118,648    | 7,524                  | 2,267                              | 958                                  |
| <b>Georgia</b>            | 3,717,100     | 323                    | 38                                 | 24                                   |
| <b>Germany</b>            | 82,695,000    | 4,553                  | 4,040                              | Not Known                            |
| <b>Ghana</b>              | 28,833,629    | 275                    | 7                                  | Not Known                            |
| <b>Greece</b>             | 10,760,421    | 1,038                  | 1,110                              | 461                                  |
| <b>Guatemala</b>          | 16,913,503    | 315                    | 23                                 | 1                                    |
| <b>Guyana</b>             | 777,859       | 11                     | Not Known                          | Not Known                            |
| <b>Honduras</b>           | 9,265,067     | 351                    | 17                                 | 2                                    |
| <b>Hong Kong (China)</b>  | 7,391,700     | 138                    | 2                                  | 4                                    |
| <b>Hungary</b>            | 9,781,127     | 1,123                  | 1,458                              | 482                                  |
| <b>India</b>              | 1,339,180,127 | 18,966                 | 563                                | 428                                  |
| <b>Indonesia</b>          | 263,991,379   | 2,054                  | 9                                  | Not Known                            |
| <b>Iran</b>               | 81,162,788    | 6,217                  | 1,585                              | 3,269                                |
| <b>Iraq</b>               | 38,274,618    | 1,402                  | 401                                | 400                                  |
| <b>Ireland</b>            | 4,813,608     | 844                    | 1,467                              | 1,214                                |
| <b>Israel</b>             | 8,712,400     | 700                    | 164                                | 719                                  |
| <b>Italy</b>              | 60,551,416    | 5,005                  | 3,262                              | 1,961                                |
| <b>Jamaica</b>            | 2,890,299     | 49                     | 1                                  | 2                                    |
| <b>Japan</b>              | 126,785,797   | 6,621                  | 1,285                              | 408                                  |
| <b>Jordan</b>             | 9,702,353     | 394                    | 252                                | 246                                  |
| <b>Kenya</b>              | 49,699,862    | 618                    | 30                                 | 20                                   |
| <b>Korea, Republic of</b> | 51,466,201    | 2,104                  | 129                                | 165                                  |
| <b>Kyrgyzstan</b>         | 6,201,500     | 377                    | 16                                 | 6                                    |

|                    | Population  | People with hemophilia | People with von Willebrand disease | People with other bleeding disorders |
|--------------------|-------------|------------------------|------------------------------------|--------------------------------------|
| Latvia             | 1,940,740   | 156                    | 120                                | 7                                    |
| <b>Lebanon</b>     | 6,082,357   | 208                    | 152                                | 70                                   |
| <b>Lesotho</b>     | 2,233,339   | 22                     | Not Known                          | Not Known                            |
| <b>Lithuania</b>   | 2,827,721   | 174                    | 303                                | 16                                   |
| <b>Madagascar</b>  | 25,570,895  | 108                    | 2                                  | 10                                   |
| <b>Malawi</b>      | 18,622,104  | 48                     | Not Known                          | Not Known                            |
| <b>Malaysia</b>    | 31,624,264  | 1,451                  | 50                                 | 43                                   |
| <b>Maldives</b>    | 436,330     | 17                     | Not Known                          | Not Known                            |
| <b>Mali</b>        | 18,541,980  | 117                    | 14                                 | 3                                    |
| <b>Mauritius</b>   | 1,264,613   | 85                     | 1                                  | 7                                    |
| <b>Mexico</b>      | 129,163,276 | 5,759                  | 306                                | 50                                   |
| <b>Moldova</b>     | 3,549,750   | 232                    | 5                                  | 1                                    |
| <b>Mongolia</b>    | 3,075,647   | 102                    | 13                                 | Not Known                            |
| Montenegro         | 622,781     | 45                     | 3                                  | 5                                    |
| Morocco            | 35,276,786  | 844                    | 17                                 | 20                                   |
| <b>Mozambique</b>  | 29,668,834  | 71                     | 1                                  | Not Known                            |
| <b>Myanmar</b>     | 53,370,609  | 39                     | 5                                  | Not Known                            |
| <b>Nepal</b>       | 29,304,998  | 624                    | 5                                  | 17                                   |
| <b>New Zealand</b> | 4,793,900   | 454                    | 237                                | 67                                   |
| <b>Nicaragua</b>   | 6,217,581   | 315                    | 89                                 | 7                                    |
| <b>Nigeria</b>     | 190,886,311 | 363                    | 7                                  | Not Known                            |
| <b>Norway</b>      | 5,282,223   | 419                    | 596                                | 88                                   |
| Oman               | 4,424,762   | 133                    | 354                                | 392                                  |
| <b>Pakistan</b>    | 197,015,955 | 1,743                  | 250                                | 121                                  |
| <b>Panama</b>      | 4,098,587   | 297                    | 505                                | 80                                   |
| <b>Paraguay</b>    | 6,811,297   | 295                    | 1                                  | 2                                    |
| <b>Philippines</b> | 104,918,090 | 1,454                  | 39                                 | Not Known                            |
| <b>Poland</b>      | 37,975,841  | 2,869                  | 1,978                              | 812                                  |
| <b>Portugal</b>    | 10,293,718  | 705                    | 51                                 | 15                                   |
| <b>Qatar</b>       | 2,639,211   | 48                     | 35                                 | 12                                   |
| Romania            | 19,705,301  | 1,825                  | 87                                 | 11                                   |
| <b>Russia</b>      | 144,495,044 | 7,451                  | 1,950                              | Not Known                            |
| Saudi Arabia       | 32,275,687  | 418                    | 182                                | 237                                  |
| <b>Senegal</b>     | 15,850,567  | 211                    | 9                                  | 5                                    |



|                        | Population  | People with hemophilia | People with von Willebrand disease | People with other bleeding disorders |
|------------------------|-------------|------------------------|------------------------------------|--------------------------------------|
| <b>Serbia</b>          | 7,022,268   | 533                    | 300                                | 52                                   |
| <b>Singapore</b>       | 5,612,253   | 256                    | 88                                 | 79                                   |
| <b>Slovak Republic</b> | 5,439,892   | 599                    | 670                                | 1,079                                |
| <b>Slovenia</b>        | 2,066,748   | 243                    | 186                                | 78                                   |
| <b>South Africa</b>    | 56,717,156  | 2,282                  | 643                                | 228                                  |
| <b>Sri Lanka</b>       | 21,444,000  | 941                    | 49                                 | 45                                   |
| <b>Sudan</b>           | 40,533,330  | 1,116                  | 282                                | 375                                  |
| <b>Sweden</b>          | 10,067,744  | 839                    | 200                                | 1                                    |
| <b>Switzerland</b>     | 8,466,017   | 418                    | 54                                 | Not Known                            |
| <b>Syria</b>           | 18,269,868  | 812                    | 98                                 | 126                                  |
| <b>Tanzania</b>        | 57,310,019  | 120                    | 1                                  | 25                                   |
| <b>Thailand</b>        | 69,037,513  | 1,588                  | 162                                | 111                                  |
| <b>Togo</b>            | 7,797,694   | 44                     | Not Known                          | Not Known                            |
| <b>Tunisia</b>         | 11,532,127  | 499                    | 156                                | 258                                  |
| <b>Uganda</b>          | 42,862,958  | 189                    | 4                                  | Not Known                            |
| <b>Ukraine</b>         | 44,831,159  | 2,188                  | 469                                | Not Known                            |
| <b>United Kingdom</b>  | 66,022,273  | 8,205                  | 10,842                             | 8,776                                |
| <b>United States</b>   | 325,719,178 | 17,750                 | 11,336                             | 4,324                                |
| <b>Uruguay</b>         | 3,456,750   | 262                    | 258                                | 25                                   |
| <b>Uzbekistan</b>      | 32,387,200  | 1,681                  | 91                                 | 38                                   |
| <b>Venezuela</b>       | 31,977,065  | 2,794                  | 1,074                              | 1,051                                |
| <b>Vietnam</b>         | 95,540,800  | 3,357                  | 146                                | 303                                  |
| <b>Zambia</b>          | 17,094,130  | 130                    | 5                                  | Not Known                            |
| <b>Zimbabwe</b>        | 16,529,904  | 150                    | Not Known                          | Not Known                            |

## Table 7. Distribution of reported bleeding disorders by country

(113 countries reported distribution of bleeding disorders)

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 2017.

|                      | 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           |                         |       |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Albania</b>       | 185          | 32           | 1                       | 6     |     |     |     |         | 4     | 2   |     | 2     |                                 |                           |                 |                                   |
| <b>Algeria</b>       | 1,875        | 419          |                         | 320   | 45  | 8   | 52  | 26      | 334   | 15  | 8   | 19    | 17                              | 29                        | 15              |                                   |
| <b>Argentina</b>     | 2,311        | 363          | 0                       | 398   |     |     |     | 1       | 2     | 0   | 1   | 1     | 0                               | 2                         | 0               | 3                                 |
| <b>Armenia</b>       | 181          | 20           |                         | 15    | 2   |     | 1   | 3       | 17    | 1   | 3   |       | 5                               | 4                         | 6               | 4                                 |
| <b>Australia</b>     | 2,123        | 512          |                         | 2,139 | 74  |     | 15  |         | 73    | 19  | 276 | 42    |                                 | 22                        | 7               | 257                               |
| <b>Austria</b>       | 678          | 120          |                         |       |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Azerbaijan</b>    | 1,163        | 141          |                         | 205   | 1   | 5   | 17  | 22      | 16    | 5   | 8   | 8     |                                 | 5                         | 9               |                                   |
| <b>Bangladesh</b>    | 1,044        | 199          | 6                       | 2     | 2   |     |     |         |       |     |     | 1     |                                 |                           |                 |                                   |
| <b>Barbados</b>      | 22           | 11           |                         | 2     |     |     | 2   |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Belarus</b>       | 526          | 120          |                         | 196   |     |     |     |         | 19    | 3   | 27  |       |                                 |                           |                 |                                   |
| <b>Belgium</b>       | 992          | 239          | 8                       | 1,972 | 2   | 2   | 21  | 0       | 127   | 9   | 130 | 4     | 28                              | 20                        | 3               | 119                               |
| <b>Belize</b>        | 13           | 5            |                         |       |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| Bolivia              | 160          | 40           |                         | 1     |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Botswana</b>      | 36           | 7            |                         | 4     |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Brazil</b>        | 10,395       | 2,037        |                         | 8,531 | 124 | 22  | 221 | 43      | 1,257 | 134 | 242 | 72    |                                 | 620                       | 90              | 418                               |
| <b>Burkina Faso</b>  | 49           | 14           |                         |       |     |     |     |         |       |     |     |       |                                 |                           |                 |                                   |
| <b>Cambodia</b>      | 142          | 22           |                         | 4     |     |     |     |         |       |     |     | 1     |                                 |                           |                 | 5                                 |
| <b>Cameroon</b>      | 126          | 24           | 0                       | 3     | 0   | 0   | 0   | 0       | 0     | 0   | 0   | 0     | 0                               | 0                         | 0               | 0                                 |
| <b>Canada</b>        | 3,293        | 730          |                         | 4,669 | 96  | 17  | 89  | 4       | 447   | 40  | 492 | 57    |                                 | 68                        | 31              |                                   |
| <b>Chile</b>         | 1,471        | 164          | 65                      | 434   | 0   | 0   | 41  | 5       | 281   | 27  | 44  | 0     | 0                               | 5                         | 4               | 367                               |
| China                | 12,533       | 1,857        |                         | 72    | 33  |     | 5   | 6       | 15    | 6   | 17  | 3     |                                 | 5                         |                 |                                   |
| <b>Colombia</b>      | 2,297        | 476          | 0                       | 1,612 | 19  | 7   | 34  | 14      | 78    | 3   | 45  | 18    | 36                              | 15                        | 2               | 26                                |
| <b>Costa Rica</b>    | 183          | 33           | 0                       | 87    | 2   | 0   | 2   | 0       | 39    | 10  | 7   | 3     |                                 |                           |                 |                                   |
| <b>Cote d'Ivoire</b> | 85           | 9            | 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                             |

|                           | Hemophilia A | Hemophilia B | Hemophilia type unknown | VWD   | FI  | FII | FV  | FV+VIII | FVII | FX  | FXI | FXIII | Bleeding Disorder: Type Unknown | Glanzmanns thrombasthenia | Bernard Soulier | Platelet Disorders: Other/Unknown |
|---------------------------|--------------|--------------|-------------------------|-------|-----|-----|-----|---------|------|-----|-----|-------|---------------------------------|---------------------------|-----------------|-----------------------------------|
| <b>Czech Republic</b>     | 936          | 141          | 0                       | 837   | 0   | 2   | 7   | 0       | 65   | 4   | 22  | 1     | 31                              |                           |                 |                                   |
| Denmark                   | 410          | 108          | 0                       | 309   | 3   | 0   | 3   | 0       | 52   | 14  | 13  | 6     | 0                               | 13                        | 7               | 34                                |
| <b>Dominican Republic</b> | 274          | 30           | 37                      | 27    |     |     |     |         | 4    | 21  |     | 6     |                                 | 2                         |                 |                                   |
| <b>Ecuador</b>            | 755          | 99           |                         | 99    |     |     |     |         | 5    |     |     | 1     |                                 |                           |                 |                                   |
| <b>Egypt</b>              | 4,695        | 1,084        |                         | 562   | 152 | 8   | 178 | 8       | 141  | 116 | 97  | 41    |                                 | 472                       | 19              |                                   |
| <b>Eritrea</b>            | 51           | 5            |                         |       |     |     |     |         |      |     |     |       |                                 |                           |                 |                                   |
| <b>Estonia</b>            | 101          | 10           |                         | 111   | 10  | 1   | 6   | 1       | 31   |     | 7   |       | 31                              |                           | 2               | 12                                |
| <b>Ethiopia</b>           | 141          | 27           | 133                     | 25    |     |     |     |         |      |     |     |       |                                 | 2                         | 1               |                                   |
| <b>Finland</b>            | 160          | 33           | 54                      | 541   |     |     |     |         |      |     |     |       |                                 |                           |                 |                                   |
| <b>France</b>             | 6,126        | 1,398        | 0                       | 2,267 | 43  | 1   | 55  | 14      | 182  | 25  | 194 | 32    | 0                               | 200                       | 49              | 163                               |
| <b>Georgia</b>            | 271          | 52           |                         | 38    | 1   |     | 1   |         | 11   |     |     | 2     |                                 | 4                         |                 | 5                                 |
| <b>Ghana</b>              | 254          | 6            | 15                      | 7     |     |     |     |         |      |     |     |       |                                 |                           |                 |                                   |
| <b>Greece</b>             | 855          | 183          | 0                       | 1,110 | 27  | 3   | 30  | 1       | 154  | 10  | 103 | 12    | 0                               | 17                        | 13              | 91                                |
| <b>Guatemala</b>          | 233          | 32           | 40                      | 23    | 0   | 0   | 0   | 0       | 9    | 0   | 1   | 0     | 0                               | 1                         | 0               | 0                                 |
| <b>Guyana</b>             | 6            |              | 5                       |       |     |     |     |         |      |     |     |       |                                 |                           |                 |                                   |
| <b>Honduras</b>           | 286          | 34           | 31                      | 17    |     |     |     |         |      |     |     | 2     |                                 |                           |                 |                                   |
| <b>Hong Kong (China)</b>  | 108          | 24           | 6                       | 2     |     |     |     |         | 2    | 2   |     |       |                                 |                           |                 |                                   |
| <b>Hungary</b>            | 896          | 227          | 0                       | 1,458 | 16  | 1   | 22  |         | 312  | 22  | 78  | 3     |                                 | 3                         |                 | 25                                |
| <b>India</b>              | 15,920       | 2,406        | 640                     | 563   | 26  | 10  | 55  | 13      | 66   | 33  | 42  | 103   |                                 | 54                        | 26              |                                   |
| <b>Indonesia</b>          | 1,787        | 267          |                         | 9     |     |     |     |         |      |     |     |       |                                 |                           |                 |                                   |
| <b>Iran</b>               | 5,121        | 1,096        | 0                       | 1,585 | 148 | 26  | 235 | 238     | 743  | 189 | 243 | 248   | 203                             | 588                       | 100             | 308                               |
| <b>Iraq</b>               | 1,044        | 358          |                         | 401   | 60  | 2   | 10  | 4       | 90   | 30  | 12  | 55    |                                 |                           |                 | 137                               |
| <b>Ireland</b>            | 606          | 238          | 0                       | 1,467 | 0   | 0   | 163 | 2       | 199  | 157 | 244 | 11    | 0                               | 12                        | 54              | 372                               |
| <b>Israel</b>             | 597          | 103          | 0                       | 164   | 5   | 0   | 9   | 14      | 90   | 9   | 372 | 8     | 0                               | 42                        | 5               | 165                               |
| <b>Italy</b>              | 4,120        | 885          |                         | 3,262 | 169 | 24  | 168 | 37      | 894  | 113 | 495 | 58    | 3                               |                           |                 |                                   |
| <b>Jamaica</b>            | 43           | 4            | 1                       | 1     |     |     |     |         |      | 3   |     |       | 0                               | 2                         |                 | 0                                 |
| <b>Japan</b>              | 5,450        | 1,171        |                         | 1,285 | 75  | 7   | 45  | 7       | 106  | 23  | 39  | 72    | 34                              |                           |                 |                                   |
| <b>Jordan</b>             | 298          | 96           |                         | 252   |     | 4   | 13  |         | 46   | 25  | 42  | 12    |                                 | 103                       | 1               |                                   |
| <b>Kenya</b>              | 504          | 114          | 0                       | 30    | 1   |     |     |         | 1    |     | 1   |       |                                 |                           |                 | 17                                |
| <b>Korea, Republic of</b> | 1,687        | 417          |                         | 129   | 5   |     | 6   | 2       | 43   | 2   | 20  | 5     | 82                              |                           |                 |                                   |

|                    | Hemophilia A | Hemophilia B | Hemophilia type unknown | VWD   | FI  | FII | FV | FV+VIII | FVII | FX | FXI | FXIII | Bleeding Disorder: Type Unknown | Glanzmanns thrombasthenia | Bernard Soulier | Platelet Disorders: Other/Unknown |
|--------------------|--------------|--------------|-------------------------|-------|-----|-----|----|---------|------|----|-----|-------|---------------------------------|---------------------------|-----------------|-----------------------------------|
| <b>Kyrgyzstan</b>  | 340          | 37           |                         | 16    | 1   | 1   |    |         |      |    |     |       |                                 | 5                         |                 |                                   |
| Latvia             | 129          | 27           | 0                       | 120   | 0   | 0   | 0  | 0       | 5    | 0  | 0   | 0     | 2                               | 0                         | 0               | 0                                 |
| <b>Lebanon</b>     | 162          | 46           | 0                       | 152   | 35  | 0   | 9  | 1       | 7    | 5  | 5   | 2     | 0                               | 1                         | 0               | 5                                 |
| <b>Lesotho</b>     | 21           | 1            |                         |       |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Lithuania</b>   | 149          | 24           | 1                       | 303   |     |     |    |         | 12   | 2  |     |       |                                 |                           |                 | 3                                 |
| <b>Madagascar</b>  | 60           | 48           |                         | 2     | 8   |     |    |         |      |    |     |       |                                 |                           |                 | 2                                 |
| <b>Malawi</b>      | 27           | 7            | 14                      |       |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Malaysia</b>    | 1,295        | 156          | 0                       | 50    | 0   | 0   | 3  | 0       | 19   | 4  | 0   | 5     | 0                               | 7                         | 0               | 5                                 |
| <b>Maldives</b>    | 13           | 4            |                         |       |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Mali</b>        | 101          | 8            | 8                       | 14    | 1   | 0   | 0  | 0       | 1    | 0  | 0   | 1     | 0                               | 0                         | 0               | 0                                 |
| <b>Mauritius</b>   | 72           | 13           | 0                       | 1     | 0   | 0   | 0  | 0       | 3    | 1  | 0   | 0     | 0                               | 3                         | 0               | 0                                 |
| <b>Mexico</b>      | 4,720        | 699          | 340                     | 306   |     | 1   | 3  |         | 26   | 5  | 4   | 2     | 4                               | 2                         |                 | 3                                 |
| <b>Moldova</b>     | 212          | 19           |                         | 5     |     |     |    |         | 1    |    |     |       |                                 |                           |                 |                                   |
| <b>Mongolia</b>    | 75           | 27           |                         | 13    |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| Montenegro         | 41           | 4            | 0                       | 3     | 0   | 0   | 0  | 0       | 1    | 0  | 1   | 3     | 0                               | 0                         | 0               | 0                                 |
| Morocco            | 663          | 181          |                         | 17    | 1   | 1   | 1  | 1       | 3    | 1  | 1   | 2     |                                 | 4                         | 1               | 4                                 |
| <b>Mozambique</b>  | 45           | 5            |                         | 1     |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Myanmar</b>     | 31           | 8            | 0                       | 5     |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Nepal</b>       | 539          | 85           |                         | 5     |     | 1   | 1  | 1       | 1    | 11 |     | 2     |                                 |                           |                 |                                   |
| <b>New Zealand</b> | 370          | 84           | 0                       | 237   | 5   | 1   | 1  | 0       | 6    | 1  | 8   | 4     | 18                              | 2                         | 1               | 20                                |
| <b>Nicaragua</b>   | 261          | 54           |                         | 89    | 4   |     |    |         |      |    |     |       | 1                               | 2                         |                 |                                   |
| <b>Nigeria</b>     | 337          | 9            | 17                      | 7     | 0   | 0   | 0  | 0       | 0    | 0  | 0   | 0     | 0                               | 0                         | 0               | 0                                 |
| <b>Norway</b>      | 329          | 90           | 0                       | 596   | 2   | 2   | 4  | 0       | 34   | 3  | 1   | 3     | 0                               | 12                        | 4               | 23                                |
| Oman               | 126          | 7            |                         | 354   | 5   | 1   | 8  | 6       | 74   | 6  | 26  | 7     | 22                              | 33                        | 2               | 202                               |
| <b>Pakistan</b>    | 1,464        | 279          | 0                       | 250   | 10  | 4   |    |         | 25   | 18 |     | 21    | 0                               | 14                        |                 | 29                                |
| <b>Panama</b>      | 264          | 33           | 0                       | 505   | 0   | 0   | 0  | 0       | 10   | 16 | 0   | 0     | 0                               | 9                         | 1               | 44                                |
| <b>Paraguay</b>    | 275          | 20           |                         | 1     |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Philippines</b> | 1,069        | 179          | 206                     | 39    |     |     |    |         |      |    |     |       |                                 |                           |                 |                                   |
| <b>Poland</b>      | 2,441        | 428          | 0                       | 1,978 | 116 | 1   | 31 | 3       | 309  | 25 | 72  | 11    | 0                               | 27                        | 9               | 208                               |
| <b>Portugal</b>    | 541          | 112          | 52                      | 51    | 2   | 0   | 3  | 0       | 2    | 1  | 6   | 1     |                                 |                           |                 |                                   |
| <b>Qatar</b>       | 45           | 5            | 0                       | 35    | 0   | 0   | 0  | 0       | 3    | 0  | 0   | 2     |                                 | 5                         | 2               | 1                                 |
| Romania            | 1,615        | 210          |                         | 87    | 1   |     |    | 2       | 2    | 2  | 2   |       | 1                               |                           | 1               |                                   |

|                        | Hemophilia A   | Hemophilia B  | Hemophilia type unknown | VWD           | F1           | FII        | FV           | FV+VIII    | FVII         | FX           | FXI          | FXIII        | Bleeding Disorder: Type Unknown | Glanzmanns thrombasthenia | Bernard Soulier | Platelet Disorders: Other/Unknown |
|------------------------|----------------|---------------|-------------------------|---------------|--------------|------------|--------------|------------|--------------|--------------|--------------|--------------|---------------------------------|---------------------------|-----------------|-----------------------------------|
| <b>Russia</b>          | 6,342          | 1,109         |                         | 1,950         |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| Saudi Arabia           | 334            | 84            | 0                       | 182           | 4            | 13         | 18           | 1          | 14           | 6            | 11           | 35           | 0                               | 119                       | 6               | 10                                |
| <b>Senegal</b>         | 185            | 26            |                         | 9             | 1            | 0          | 1            | 0          | 2            | 1            | 0            | 0            |                                 |                           |                 |                                   |
| <b>Serbia</b>          | 450            | 83            | 0                       | 300           | 6            | 0          | 2            | 2          | 26           | 1            | 8            | 4            | 1                               | 0                         | 2               |                                   |
| <b>Singapore</b>       | 210            | 46            | 0                       | 88            | 0            | 0          | 18           | 0          | 9            | 0            | 47           | 5            | 0                               | 0                         | 0               | 0                                 |
| <b>Slovak Republic</b> | 523            | 76            | 0                       | 670           | 90           | 0          | 74           | 1          | 775          | 37           | 52           | 2            | 0                               | 10                        | 15              | 23                                |
| <b>Slovenia</b>        | 213            | 30            | 0                       | 186           | 3            | 0          | 12           | 3          | 16           | 2            | 20           | 0            | 0                               | 8                         | 0               | 14                                |
| <b>South Africa</b>    | 1,917          | 365           | 0                       | 643           | 10           | 0          | 43           | 6          | 18           | 9            | 27           | 8            | 0                               | 22                        | 27              | 58                                |
| <b>Sri Lanka</b>       | 769            | 172           |                         | 49            | 1            | 1          | 10           |            | 3            |              | 10           | 2            |                                 | 9                         |                 | 9                                 |
| <b>Sudan</b>           | 913            | 203           |                         | 282           | 41           | 3          | 54           | 3          | 38           | 29           | 5            | 25           | 5                               |                           |                 | 170                               |
| <b>Sweden</b>          | 663            | 176           |                         | 200           |              |            |              |            |              |              |              |              |                                 | 1                         |                 |                                   |
| <b>Syria</b>           | 731            | 81            |                         | 98            | 16           |            | 9            | 32         | 22           | 3            |              | 1            |                                 | 29                        | 3               | 11                                |
| <b>Tanzania</b>        | 81             | 14            | 25                      |               |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| <b>Thailand</b>        | 1,404          | 184           |                         | 162           | 1            |            | 10           | 5          | 28           | 6            | 8            | 8            |                                 | 17                        | 10              | 18                                |
| <b>Togo</b>            | 30             | 9             | 5                       |               |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| <b>Uganda</b>          | 160            | 29            |                         | 4             |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| <b>Ukraine</b>         | 1,860          | 328           |                         | 469           |              |            |              |            |              | 1            |              |              |                                 |                           |                 |                                   |
| <b>United Kingdom</b>  | 6,713          | 1,492         | 0                       | 10,842        | 734          | 14         | 216          | 28         | 1,373        | 262          | 3,204        | 70           | 0                               | 142                       | 91              | 2,642                             |
| <b>United States</b>   | 13,639         | 4,111         |                         | 11,336        | 170          | 25         | 119          | 23         | 865          | 109          | 495          | 116          |                                 | 167                       | 36              | 2,199                             |
| <b>Uruguay</b>         | 222            | 40            |                         | 258           |              |            | 1            |            | 6            |              | 9            |              |                                 | 1                         | 4               |                                   |
| <b>Uzbekistan</b>      | 1,519          | 155           | 7                       | 91            |              |            |              |            | 10           |              | 6            | 5            |                                 | 16                        | 1               |                                   |
| <b>Venezuela</b>       | 2,217          | 577           |                         | 1,074         | 20           | 66         | 35           | 28         | 179          | 111          | 394          | 16           | 6                               | 17                        | 4               | 175                               |
| <b>Vietnam</b>         | 2,773          | 584           | 0                       | 146           | 6            | 5          | 9            | 11         | 44           | 20           | 12           | 12           | 3                               | 85                        | 3               | 93                                |
| <b>Zambia</b>          | 83             | 20            | 27                      | 5             |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| <b>Zimbabwe</b>        | 135            | 15            |                         |               |              |            |              |            |              |              |              |              |                                 |                           |                 |                                   |
| <b>Total</b>           | <b>158,225</b> | <b>31,247</b> | <b>1,744</b>            | <b>71,893</b> | <b>2,437</b> | <b>291</b> | <b>2,203</b> | <b>622</b> | <b>9,930</b> | <b>1,774</b> | <b>7,774</b> | <b>1,291</b> | <b>550</b>                      | <b>3,082</b>              | <b>667</b>      | <b>11,668</b>                     |

## 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                                  | <b>113</b>          | 158,225                   | 142,702 | <b>90</b>    | 4,874  | <b>3</b>       | 8,789            | <b>6</b>          |
| Hemophilia B                                  | <b>112</b>          | 31,247                    | 27,427  | <b>88</b>    | 1,584  | <b>5</b>       | 1,736            | <b>6</b>          |
| Hemophilia type unknown                       | <b>60</b>           | 1,744                     | 1,499   | <b>86</b>    | 169    | <b>10</b>      | 61               | <b>3</b>          |
| von Willebrand disease (VWD)                  | <b>101</b>          | 71,893                    | 26,450  | <b>37</b>    | 41,026 | <b>57</b>      | 3,737            | <b>5</b>          |
| Factor I Deficiency                           | <b>68</b>           | 2,437                     | 1,026   | <b>42</b>    | 1,249  | <b>51</b>      | 160              | <b>7</b>          |
| Factor II Deficiency                          | <b>59</b>           | 291                       | 138     | <b>47</b>    | 140    | <b>48</b>      | 12               | <b>4</b>          |
| Factor V Deficiency                           | <b>66</b>           | 2,203                     | 944     | <b>43</b>    | 1,038  | <b>47</b>      | 200              | <b>9</b>          |
| Factor V+VIII Deficiency                      | <b>60</b>           | 622                       | 323     | <b>52</b>    | 267    | <b>43</b>      | 24               | <b>4</b>          |
| Factor VII Deficiency                         | <b>77</b>           | 9,930                     | 4,765   | <b>48</b>    | 4,793  | <b>48</b>      | 335              | <b>3</b>          |
| Factor X Deficiency                           | <b>71</b>           | 1,774                     | 821     | <b>46</b>    | 782    | <b>44</b>      | 164              | <b>9</b>          |
| Factor XI Deficiency                          | <b>71</b>           | 7,741                     | 3,149   | <b>41</b>    | 4,061  | <b>52</b>      | 523              | <b>7</b>          |
| Factor XIII Deficiency                        | <b>71</b>           | 1,291                     | 650     | <b>50</b>    | 564    | <b>44</b>      | 67               | <b>5</b>          |
| Bleeding disorder: type unknown               | <b>48</b>           | 550                       | 239     | <b>43</b>    | 305    | <b>55</b>      | 1                | <b>0</b>          |
| Platelet disorders: Glanzmanns thrombasthenia | <b>63</b>           | 3,082                     | 1,048   | <b>34</b>    | 1,168  | <b>38</b>      | 841              | <b>27</b>         |
| Platelet disorder: Bernard Soulier syndrome   | <b>54</b>           | 667                       | 244     | <b>37</b>    | 328    | <b>49</b>      | 81               | <b>12</b>         |
| Platelet Disorders: other or unknown          | <b>55</b>           | 11,668                    | 2,942   | <b>25</b>    | 4,959  | <b>43</b>      | 3,737            | <b>32</b>         |

A woman who has  $\leq 40\%$  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**

(91 countries reported number of inhibitors)

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 2017) | Hemophilia B inhibitors (total) | Hemophilia B inhibitors (new cases in 2017) |
|--------------------|---------------------------------|---|---------------------------------|---|
| Albania            | 8                               | 0   | 2                               | 1   |
| Argentina          | 92                              | 7   | 5                               | 0   |
| Armenia            | 3                               | 0   |                                 |   |
| Australia          | 65                              | 4   | 3                               | 0   |
| Austria            | 23                              | 2   | 1                               | 0   |
| Azerbaijan         | 24                              | 2   |                                 |   |
| Barbados           |                                 |   | 1                               |   |
| Belarus            | 53                              |   | 6                               |   |
| Belize             |                                 | 0   |                                 | 0   |
| Botswana           | 2                               |   |                                 |   |
| Brazil             | 384                             | 66  | 43                              | 4   |
| Burkina Faso       | 1                               | 1   |                                 |   |
| Cambodia           | 2                               | 0   | 0                               | 0   |
| Cameroon           | 13                              | 0   | 2                               | 0   |
| Canada             | 81                              |   | 1                               |   |
| Chile              | 28                              | 5   | 2                               | 1   |
| Colombia           | 160                             | 2   | 16                              | 0   |
| Costa Rica         | 11                              | 0   | 0                               | 0   |
| Cote d'Ivoire      | 5                               | 0   | 0                               | 0   |
| Czech Republic     | 22                              | 2   | 2                               | 0   |
| Dominican Republic | 12                              | 1   |                                 |   |
| Ecuador            | 19                              | 7   |                                 |   |
| Egypt              | 142                             | 54  | 2                               | 0   |
| Estonia            | 4                               | 0   |                                 |   |
| Finland            | 13                              | 1   | 2                               |   |
| France             | 153                             | 9   | 5                               | 0   |

|                    | Hemophilia A inhibitors (total) | Hemophilia A inhibitors (new cases in 2017) | Hemophilia B inhibitors (total) | Hemophilia B inhibitors (new cases in 2017) |
|--------------------|---------------------------------|---|---------------------------------|---|
| Georgia            | 8                               |   |                                 |   |
| Germany            | 187                             |   | 29                              |   |
| Ghana              | 1                               | 1   | 0                               | 0   |
| Greece             | 16                              | 1   | 3                               | 0   |
| Guatemala          | 15                              | 15  | 0                               | 0   |
| Honduras           | 10                              | 0   |                                 |   |
| Hong Kong (China)  | 8                               |   | 1                               |   |
| Hungary            | 20                              | 1   | 0                               | 0   |
| India              | 776                             |   | 18                              |   |
| Indonesia          | 2                               | 2   | 1                               | 1   |
| Iran               | 256                             | 25  | 17                              | 3   |
| Iraq               | 92                              | 7   | 4                               | 1   |
| Ireland            |                                 |   | 3                               | 1   |
| Israel             | 20                              | 6   | 2                               | 0   |
| Italy              | 373                             |   | 12                              |   |
| Jamaica            | 14                              | 1   | 0                               | 0   |
| Jordan             | 22                              | 4   | 0                               | 2   |
| Kenya              | 12                              | 8   | 0                               | 0   |
| Korea, Republic of | 47                              | 3   | 5                               |   |
| Kyrgyzstan         | 1                               | 0   |                                 |   |
| Lebanon            | 10                              | 2   | 0                               | 0   |
| Lithuania          | 8                               |   |                                 |   |
| Madagascar         | 2                               | 0   | 0                               | 0   |
| Malaysia           | 83                              | 2   | 8                               | 0   |
| Mali               | 2                               | 1   | 0                               | 0   |
| Mauritius          | 1                               | 0   | 0                               | 0   |
| Mexico             | 266                             | 0   | 14                              | 0   |
| Moldova            |                                 |   | 1                               | 0   |
| Mozambique         | 1                               | 1   |                                 |   |
| Myanmar            | 16                              | 7   |                                 |   |
| Nepal              | 15                              | 3   |                                 |   |
| New Zealand        | 16                              | 1   | 0                               | 0   |
| Nicaragua          | 2                               |   |                                 |   |
| Nigeria            | 2                               | 1   | 0                               | 0   |



|                 | Hemophilia A inhibitors (total) | Hemophilia A inhibitors (new cases in 2017) | Hemophilia B inhibitors (total) | Hemophilia B inhibitors (new cases in 2017) |
|-----------------|---------------------------------|---|---------------------------------|---|
| Norway          | 12                              | 2   | 1                               | 0   |
| Pakistan        | 13                              | 0   | 1                               | 0   |
| Panama          | 4                               | 1   | 0                               | 0   |
| Paraguay        | 1                               |   |                                 |   |
| Philippines     | 16                              | 11  | 1                               | 0   |
| Poland          | 148                             |   | 4                               |   |
| Qatar           | 2                               | 4   | 1                               | 1   |
| Russia          | 200                             |   | 2                               |   |
| Senegal         | 7                               | 2   | 0                               | 0   |
| Serbia          | 16                              | 0   | 0                               | 0   |
| Singapore       | 5                               | 0   | 0                               | 0   |
| Slovak Republic | 6                               | 1   | 1                               |   |
| Slovenia        | 3                               | 0   | 0                               | 0   |
| South Africa    | 172                             | 5   | 10                              | 0   |
| Sri Lanka       | 67                              | 15  |                                 |   |
| Sudan           | 8                               | 1   |                                 |   |
| Sweden          | 35                              |   | 2                               |   |
| Switzerland     | 94                              |   |                                 |   |
| Syria           | 36                              | 1   | 1                               | 0   |
| Tanzania        | 3                               |   |                                 |   |
| Thailand        | 64                              | 27  |                                 |   |
| Tunisia         | 25                              | 1   | 1                               |   |
| Uganda          | 0                               |   | 0                               |   |
| Ukraine         | 74                              |   | 3                               |   |
| United Kingdom  | 212                             | 25  | 13                              | 1   |
| United States   | 839                             |   | 87                              |   |
| Uruguay         | 9                               |   | 2                               |   |
| Uzbekistan      | 38                              | 2   |                                 |   |
| Venezuela       | 101                             | 3   | 1                               | 0   |
| Vietnam         | 109                             | 13  | 0                               | 0   |
| Zimbabwe        | 5                               | 1   |                                 |   |
| <b>Total</b>    | <b>5,948</b>                    | <b>370</b>                                  | <b>342</b>                      | <b>16</b>                                   |

## Table 10. Age distribution: Hemophilia A

(91 countries reported age data for hemophilia A)

|                    | Hemophilia A | 0–4 | 5–13 | 14–18 | 19–44 | 45+ | Age Not Known |
|--------------------|--------------|-----|------|-------|-------|-----|---------------|
| Albania            | 185          | 4%  | 22%  | 11%   | 41%   | 22% | 0%            |
| Argentina          | 2,311        | 4%  | 16%  | 9%    | 45%   | 22% | 5%            |
| Armenia            | 123          | 7%  | 34%  | 3%    | 45%   | 11% | 0%            |
| Australia          | 2,123        | 6%  | 15%  | 7%    | 38%   | 34% | 0%            |
| Austria            | 678          | 3%  | 9%   | 9%    | 42%   | 36% | 0%            |
| Azerbaijan         | 1,163        | 3%  | 10%  | 41%   | 38%   | 8%  | 0%            |
| Bangladesh         | 1,044        | 10% | 32%  | 22%   | 32%   | 3%  | 0%            |
| Barbados           | 22           | 0%  | 14%  | 0%    | 59%   | 27% | 0%            |
| Belarus            | 526          | 5%  | 9%   | 7%    | 45%   | 34% | 0%            |
| Belgium            | 991          | 2%  | 10%  | 8%    | 36%   | 43% | 0%            |
| Belize             | 13           | 8%  | 23%  | 38%   | 31%   | 0%  | 0%            |
| Botswana           | 36           | 17% | 22%  | 19%   | 28%   | 3%  | 11%           |
| Brazil             | 10,395       | 6%  | 16%  | 10%   | 49%   | 18% | 0%            |
| Burkina Faso       | 49           | 27% | 45%  | 8%    | 16%   | 0%  | 4%            |
| Cambodia           | 142          | 17% | 45%  | 19%   | 19%   | 0%  | 0%            |
| Cameroon           | 126          | 18% | 32%  | 26%   | 16%   | 8%  | 0%            |
| Canada             | 3,293        | 2%  | 13%  | 8%    | 42%   | 35% | 0%            |
| Chile              | 1,471        | 2%  | 13%  | 11%   | 49%   | 22% | 2%            |
| Colombia           | 2,297        | 2%  | 23%  | 11%   | 59%   | 5%  | 0%            |
| Costa Rica         | 183          | 7%  | 19%  | 11%   | 51%   | 12% | 0%            |
| Cote d'Ivoire      | 85           | 19% | 29%  | 22%   | 26%   | 4%  | 0%            |
| Czech Republic     | 936          | 4%  | 12%  | 6%    | 45%   | 33% | 0%            |
| Dominican Republic | 274          | 4%  | 20%  | 12%   | 42%   | 10% | 11%           |
| Egypt              | 4,695        | 10% | 42%  | 4%    | 10%   | 2%  | 32%           |
| Eritrea            | 51           | 0%  | 22%  | 22%   | 51%   | 2%  | 4%            |
| Estonia            | 101          | 5%  | 9%   | 4%    | 62%   | 20% | 0%            |
| Ethiopia           | 141          | 8%  | 38%  | 14%   | 38%   | 2%  | 0%            |
| France             | 6,126        | 8%  | 16%  | 10%   | 39%   | 26% | 0%            |
| Georgia            | 271          | 10% | 18%  | 7%    | 47%   | 18% | 0%            |
| Ghana              | 254          | 10% | 47%  | 18%   | 13%   | 0%  | 12%           |

|                    | Hemophilia A | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|--------------------|--------------|-----|------|-------|-------|-----|---------------|
| Greece             | 855          | 3%  | 8%   | 6%    | 39%   | 43% | 0%            |
| Guatemala          | 233          | 4%  | 18%  | 16%   | 45%   | 8%  | 10%           |
| Guyana             | 6            | 0%  | 0%   | 17%   | 83%   | 0%  | 0%            |
| Honduras           | 286          | 4%  | 29%  | 15%   | 42%   | 3%  | 7%            |
| Hong Kong (China)  | 108          | 3%  | 17%  | 6%    | 65%   | 8%  | 2%            |
| Hungary            | 896          | 3%  | 8%   | 4%    | 42%   | 43% | 0%            |
| India              | 15,920       | 1%  | 14%  | 11%   | 41%   | 9%  | 24%           |
| Indonesia          | 1,784        | 6%  | 31%  | 20%   | 34%   | 3%  | 5%            |
| Iran               | 5,121        | 3%  | 13%  | 8%    | 57%   | 19% | 0%            |
| Iraq               | 1,044        | 23% | 38%  | 19%   | 16%   | 3%  | 0%            |
| Ireland            | 606          | 4%  | 18%  | 9%    | 38%   | 32% | 0%            |
| Israel             | 597          | 8%  | 17%  | 10%   | 41%   | 23% | 0%            |
| Jamaica            | 44           | 5%  | 16%  | 23%   | 34%   | 23% | 0%            |
| Kenya              | 504          | 12% | 29%  | 27%   | 14%   | 13% | 4%            |
| Korea, Republic of | 1,687        | 5%  | 11%  | 9%    | 54%   | 22% | 0%            |
| Kyrgyzstan         | 267          | 7%  | 39%  | 15%   | 32%   | 8%  | 0%            |
| Lebanon            | 162          | 9%  | 16%  | 12%   | 47%   | 16% | 0%            |
| Lesotho            | 21           | 5%  | 19%  | 33%   | 43%   | 0%  | 0%            |
| Madagascar         | 60           | 7%  | 37%  | 18%   | 35%   | 3%  | 0%            |
| Malaysia           | 1,295        | 4%  | 8%   | 8%    | 38%   | 24% | 18%           |
| Maldives           | 12           | 8%  | 33%  | 17%   | 25%   | 17% | 0%            |
| Mali               | 101          | 22% | 44%  | 19%   | 16%   | 0%  | 0%            |
| Mauritius          | 72           | 0%  | 13%  | 10%   | 42%   | 31% | 6%            |
| Mexico             | 4,720        | 3%  | 20%  | 12%   | 41%   | 10% | 14%           |
| Moldova            | 212          | 0%  | 4%   | 6%    | 45%   | 45% | 0%            |
| Mongolia           | 75           | 13% | 43%  | 7%    | 32%   | 5%  | 0%            |
| Mozambique         | 70           | 4%  | 4%   | 4%    | 84%   | 3%  | 0%            |
| Myanmar            | 31           | 39% | 35%  | 3%    | 23%   | 0%  | 0%            |
| Nepal              | 539          | 8%  | 21%  | 18%   | 36%   | 6%  | 12%           |
| New Zealand        | 370          | 3%  | 15%  | 9%    | 39%   | 24% | 10%           |
| Nicaragua          | 261          | 12% | 29%  | 16%   | 25%   | 2%  | 17%           |
| Nigeria            | 337          | 9%  | 34%  | 15%   | 23%   | 2%  | 16%           |
| Norway             | 331          | 5%  | 16%  | 8%    | 38%   | 33% | 0%            |
| Pakistan           | 1,464        | 6%  | 23%  | 13%   | 33%   | 3%  | 21%           |

|                 | Hemophilia A | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|-----------------|--------------|-----|------|-------|-------|-----|---------------|
| Panama          | 264          | 6%  | 15%  | 10%   | 52%   | 18% | 0%            |
| Paraguay        | 275          | 7%  | 9%   | 16%   | 20%   | 47% | 0%            |
| Philippines     | 1,069        | 4%  | 12%  | 14%   | 49%   | 8%  | 13%           |
| Poland          | 2,441        | 1%  | 7%   | 4%    | 47%   | 39% | 0%            |
| Portugal        | 541          | 1%  | 9%   | 8%    | 41%   | 33% | 8%            |
| Qatar           | 43           | 9%  | 26%  | 30%   | 33%   | 2%  | 0%            |
| Senegal         | 185          | 9%  | 37%  | 21%   | 30%   | 3%  | 0%            |
| Serbia          | 450          | 4%  | 12%  | 7%    | 48%   | 29% | 0%            |
| Singapore       | 210          | 6%  | 9%   | 9%    | 41%   | 36% | 0%            |
| Slovak Republic | 523          | 3%  | 11%  | 5%    | 47%   | 34% | 0%            |
| Slovenia        | 213          | 3%  | 9%   | 3%    | 34%   | 42% | 8%            |
| South Africa    | 1,917        | 4%  | 18%  | 9%    | 42%   | 24% | 2%            |
| Sri Lanka       | 768          | 18% | 18%  | 7%    | 24%   | 4%  | 29%           |
| Sudan           | 913          | 20% | 35%  | 14%   | 27%   | 3%  | 0%            |
| Sweden          | 655          | 3%  | 17%  | 10%   | 40%   | 31% | 0%            |
| Syria           | 727          | 15% | 28%  | 15%   | 35%   | 5%  | 2%            |
| Thailand        | 1,404        | 23% | 34%  | 19%   | 19%   | 4%  | 0%            |
| Togo            | 30           | 23% | 23%  | 10%   | 27%   | 7%  | 10%           |
| Uganda          | 160          | 26% | 43%  | 10%   | 19%   | 3%  | 0%            |
| United Kingdom  | 6,713        | 6%  | 13%  | 7%    | 38%   | 36% | 0%            |
| United States   | 13,639       | 9%  | 24%  | 12%   | 33%   | 21% | 0%            |
| Uruguay         | 222          | 5%  | 13%  | 8%    | 50%   | 24% | 0%            |
| Uzbekistan      | 1,519        | 5%  | 17%  | 9%    | 58%   | 11% | 0%            |
| Venezuela       | 2,217        | 4%  | 13%  | 9%    | 39%   | 17% | 17%           |
| Vietnam         | 2,773        | 7%  | 22%  | 11%   | 48%   | 9%  | 3%            |
| Zambia          | 110          | 12% | 14%  | 22%   | 20%   | 3%  | 30%           |
| Zimbabwe        | 135          | 5%  | 16%  | 16%   | 50%   | 7%  | 7%            |

## Table 11. Age distribution: Hemophilia B

(90 countries reported age data for hemophilia B)

|                    | Hemophilia B | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|--------------------|--------------|-----|------|-------|-------|-----|---------------|
| Albania            | 32           | 9%  | 6%   | 0%    | 72%   | 13% | 0%            |
| Argentina          | 363          | 4%  | 17%  | 9%    | 45%   | 17% | 8%            |
| Armenia            | 20           | 15% | 10%  | 5%    | 35%   | 35% | 0%            |
| Australia          | 512          | 4%  | 12%  | 7%    | 40%   | 37% | 0%            |
| Austria            | 120          | 4%  | 11%  | 3%    | 47%   | 35% | 0%            |
| Azerbaijan         | 141          | 9%  | 11%  | 26%   | 47%   | 8%  | 0%            |
| Bangladesh         | 199          | 10% | 37%  | 22%   | 28%   | 3%  | 0%            |
| Barbados           | 11           | 0%  | 9%   | 9%    | 64%   | 18% | 0%            |
| Belarus            | 120          | 1%  | 10%  | 7%    | 48%   | 35% | 0%            |
| Belgium            | 239          | 2%  | 10%  | 6%    | 35%   | 47% | 0%            |
| Belize             | 5            | 0%  | 0%   | 40%   | 60%   | 0%  | 0%            |
| Botswana           | 7            | 0%  | 57%  | 0%    | 29%   | 0%  | 14%           |
| Brazil             | 2,037        | 5%  | 15%  | 12%   | 48%   | 19% | 0%            |
| Burkina Faso       | 14           | 14% | 36%  | 21%   | 21%   | 0%  | 7%            |
| Cambodia           | 22           | 18% | 50%  | 14%   | 18%   | 0%  | 0%            |
| Cameroon           | 24           | 25% | 38%  | 21%   | 17%   | 0%  | 0%            |
| Canada             | 730          | 2%  | 10%  | 6%    | 41%   | 41% | 0%            |
| Chile              | 164          | 1%  | 13%  | 8%    | 52%   | 22% | 4%            |
| Colombia           | 476          | 2%  | 22%  | 10%   | 59%   | 7%  | 0%            |
| Costa Rica         | 33           | 3%  | 15%  | 9%    | 61%   | 12% | 0%            |
| Cote d'Ivoire      | 9            | 11% | 44%  | 11%   | 22%   | 11% | 0%            |
| Czech Republic     | 141          | 6%  | 11%  | 6%    | 35%   | 41% | 0%            |
| Dominican Republic | 30           | 0%  | 17%  | 7%    | 50%   | 17% | 10%           |
| Egypt              | 1,084        | 6%  | 43%  | 2%    | 8%    | 1%  | 40%           |
| Eritrea            | 5            | 0%  | 40%  | 0%    | 60%   | 0%  | 0%            |
| Estonia            | 10           | 10% | 30%  | 0%    | 30%   | 30% | 0%            |
| Ethiopia           | 27           | 7%  | 26%  | 11%   | 52%   | 4%  | 0%            |
| France             | 1,398        | 8%  | 18%  | 10%   | 37%   | 26% | 0%            |
| Georgia            | 52           | 13% | 13%  | 8%    | 44%   | 21% | 0%            |
| Ghana              | 6            | 0%  | 100% | 0%    | 0%    | 0%  | 0%            |

|                    | Hemophilia B | 0-4  | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|--------------------|--------------|------|------|-------|-------|-----|---------------|
| Greece             | 183          | 4%   | 7%   | 4%    | 37%   | 48% | 0%            |
| Guatemala          | 32           | 3%   | 9%   | 19%   | 31%   | 3%  | 34%           |
| Honduras           | 34           | 6%   | 24%  | 21%   | 38%   | 3%  | 9%            |
| Hong Kong (China)  | 24           | 0%   | 21%  | 8%    | 46%   | 25% | 0%            |
| Hungary            | 227          | 1%   | 4%   | 7%    | 42%   | 45% | 0%            |
| India              | 2,406        | 1%   | 12%  | 13%   | 46%   | 12% | 16%           |
| Indonesia          | 270          | 8%   | 37%  | 30%   | 24%   | 2%  | 0%            |
| Iran               | 1,096        | 3%   | 11%  | 8%    | 59%   | 19% | 0%            |
| Iraq               | 358          | 18%  | 36%  | 24%   | 16%   | 7%  | 0%            |
| Ireland            | 238          | 4%   | 16%  | 9%    | 40%   | 31% | 0%            |
| Israel             | 103          | 17%  | 15%  | 17%   | 35%   | 17% | 0%            |
| Jamaica            | 4            | 0%   | 0%   | 25%   | 50%   | 25% | 0%            |
| Kenya              | 114          | 18%  | 25%  | 31%   | 21%   | 4%  | 2%            |
| Korea, Republic of | 417          | 4%   | 14%  | 12%   | 48%   | 23% | 0%            |
| Kyrgyzstan         | 37           | 5%   | 14%  | 14%   | 62%   | 5%  | 0%            |
| Lebanon            | 46           | 7%   | 15%  | 22%   | 48%   | 9%  | 0%            |
| Lesotho            | 1            | 0%   | 100% | 0%    | 0%    | 0%  | 0%            |
| Madagascar         | 48           | 13%  | 52%  | 10%   | 25%   | 0%  | 0%            |
| Malaysia           | 156          | 10%  | 19%  | 21%   | 27%   | 18% | 6%            |
| Maldives           | 5            | 60%  | 0%   | 20%   | 0%    | 20% | 0%            |
| Mali               | 8            | 63%  | 0%   | 13%   | 25%   | 0%  | 0%            |
| Mauritius          | 13           | 8%   | 15%  | 15%   | 46%   | 15% | 0%            |
| Mexico             | 699          | 4%   | 19%  | 12%   | 43%   | 10% | 12%           |
| Moldova            | 19           | 0%   | 5%   | 0%    | 68%   | 26% | 0%            |
| Mongolia           | 27           | 11%  | 37%  | 19%   | 26%   | 7%  | 0%            |
| Mozambique         | 1            | 100% | 0%   | 0%    | 0%    | 0%  | 0%            |
| Myanmar            | 8            | 50%  | 38%  | 0%    | 13%   | 0%  | 0%            |
| Nepal              | 85           | 9%   | 33%  | 16%   | 29%   | 9%  | 2%            |
| New Zealand        | 84           | 2%   | 11%  | 4%    | 37%   | 37% | 10%           |
| Nicaragua          | 54           | 6%   | 11%  | 17%   | 15%   | 2%  | 50%           |
| Nigeria            | 9            | 22%  | 33%  | 11%   | 11%   | 0%  | 22%           |
| Norway             | 88           | 5%   | 15%  | 16%   | 30%   | 35% | 0%            |
| Pakistan           | 279          | 6%   | 21%  | 14%   | 32%   | 3%  | 25%           |
| Panama             | 33           | 6%   | 12%  | 24%   | 48%   | 9%  | 0%            |

|                 | Hemophilia B | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|-----------------|--------------|-----|------|-------|-------|-----|---------------|
| Paraguay        | 20           | 5%  | 25%  | 50%   | 15%   | 5%  | 0%            |
| Philippines     | 179          | 3%  | 15%  | 14%   | 51%   | 7%  | 10%           |
| Poland          | 426          | 2%  | 7%   | 6%    | 50%   | 35% | 1%            |
| Portugal        | 112          | 1%  | 9%   | 6%    | 39%   | 37% | 8%            |
| Qatar           | 5            | 20% | 20%  | 60%   | 0%    | 0%  | 0%            |
| Senegal         | 26           | 8%  | 81%  | 8%    | 0%    | 4%  | 0%            |
| Serbia          | 83           | 4%  | 18%  | 10%   | 47%   | 22% | 0%            |
| Singapore       | 46           | 2%  | 15%  | 9%    | 52%   | 22% | 0%            |
| Slovak Republic | 76           | 4%  | 18%  | 7%    | 50%   | 21% | 0%            |
| Slovenia        | 30           | 3%  | 10%  | 0%    | 33%   | 37% | 17%           |
| South Africa    | 365          | 4%  | 32%  | 10%   | 33%   | 20% | 1%            |
| Sri Lanka       | 163          | 20% | 23%  | 10%   | 3%    | 3%  | 40%           |
| Sudan           | 203          | 19% | 42%  | 14%   | 24%   | 1%  | 0%            |
| Sweden          | 184          | 1%  | 13%  | 5%    | 36%   | 45% | 0%            |
| Syria           | 81           | 12% | 30%  | 23%   | 31%   | 1%  | 2%            |
| Thailand        | 184          | 58% | 17%  | 9%    | 9%    | 8%  | 0%            |
| Togo            | 9            | 0%  | 33%  | 22%   | 11%   | 0%  | 33%           |
| Uganda          | 29           | 24% | 34%  | 14%   | 28%   | 0%  | 0%            |
| United Kingdom  | 1,492        | 6%  | 13%  | 6%    | 39%   | 35% | 0%            |
| United States   | 4,111        | 10% | 24%  | 11%   | 29%   | 26% | 0%            |
| Uruguay         | 40           | 5%  | 18%  | 13%   | 53%   | 13% | 0%            |
| Uzbekistan      | 155          | 4%  | 19%  | 12%   | 55%   | 10% | 0%            |
| Venezuela       | 577          | 2%  | 13%  | 7%    | 40%   | 21% | 17%           |
| Vietnam         | 584          | 8%  | 18%  | 11%   | 48%   | 12% | 3%            |
| Zambia          | 20           | 35% | 5%   | 45%   | 15%   | 0%  | 0%            |
| Zimbabwe        | 15           | 0%  | 27%  | 7%    | 40%   | 13% | 13%           |

## Table 12. Age distribution: Hemophilia Type Unknown

(21 countries reported age data)

|                    | Hemophilia Type Unknown | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|--------------------|-------------------------|-----|------|-------|-------|-----|---------------|
| Albania            | 1                       | 0%  | 0%   | 0%    | 100%  | 0%  | 0%            |
| Armenia            | 2                       | 0%  | 0%   | 0%    | 100%  | 0%  | 0%            |
| Bangladesh         | 6                       | 0%  | 0%   | 100%  | 0%    | 0%  | 0%            |
| Belgium            | 9                       | 0%  | 0%   | 0%    | 22%   | 67% | 11%           |
| Dominican Republic | 70                      | 0%  | 13%  | 7%    | 27%   | 6%  | 47%           |
| Ethiopia           | 133                     | 17% | 34%  | 21%   | 29%   | 0%  | 0%            |
| Ghana              | 15                      | 67% | 33%  | 0%    | 0%    | 0%  | 0%            |
| Guatemala          | 51                      | 2%  | 6%   | 2%    | 2%    | 0%  | 88%           |
| Guyana             | 5                       | 20% | 20%  | 0%    | 60%   | 0%  | 0%            |
| Honduras           | 31                      | 16% | 19%  | 13%   | 19%   | 0%  | 32%           |
| Hong Kong (China)  | 6                       | 0%  | 0%   | 0%    | 50%   | 17% | 33%           |
| India              | 640                     | 1%  | 5%   | 8%    | 26%   | 6%  | 53%           |
| Mali               | 8                       | 25% | 50%  | 13%   | 0%    | 13% | 0%            |
| Mexico             | 340                     | 1%  | 9%   | 6%    | 21%   | 4%  | 61%           |
| Moldova            | 1                       | 0%  | 0%   | 0%    | 100%  | 0%  | 0%            |
| Nigeria            | 17                      | 53% | 12%  | 0%    | 18%   | 0%  | 18%           |
| Philippines        | 206                     | 2%  | 10%  | 13%   | 43%   | 5%  | 27%           |
| Portugal           | 52                      | 0%  | 0%   | 8%    | 21%   | 29% | 42%           |
| Syria              | 4                       | 50% | 25%  | 25%   | 0%    | 0%  | 0%            |
| Togo               | 5                       | 0%  | 60%  | 0%    | 20%   | 0%  | 20%           |
| Uzbekistan         | 7                       | 57% | 43%  | 0%    | 0%    | 0%  | 0%            |



## Table 13. Age distribution: VWD

(74 countries reported age data)

|                    | VWD   | 0–4 | 5–13 | 14–18 | 19–44 | 45+  | Age Not Known |
|--------------------|-------|-----|------|-------|-------|------|---------------|
| Albania            | 6     | 0%  | 17%  | 0%    | 83%   | 0%   | 0%            |
| Argentina          | 398   | 0%  | 2%   | 3%    | 45%   | 36%  | 14%           |
| Armenia            | 15    | 0%  | 7%   | 20%   | 53%   | 0%   | 20%           |
| Australia          | 2,139 | 2%  | 9%   | 7%    | 45%   | 37%  | 0%            |
| Azerbaijan         | 205   | 3%  | 5%   | 27%   | 32%   | 33%  | 0%            |
| Bangladesh         | 2     | 50% | 0%   | 0%    | 50%   | 0%   | 0%            |
| Barbados           | 2     | 0%  | 0%   | 0%    | 100%  | 0%   | 0%            |
| Belarus            | 196   | 1%  | 3%   | 5%    | 66%   | 26%  | 0%            |
| Belgium            | 1,972 | 0%  | 14%  | 10%   | 41%   | 34%  | 1%            |
| Botswana           | 4     | 0%  | 75%  | 25%   | 0%    | 0%   | 0%            |
| Brazil             | 8,531 | 1%  | 11%  | 10%   | 52%   | 26%  | 0%            |
| Cambodia           | 4     | 25% | 75%  | 0%    | 0%    | 0%   | 0%            |
| Cameroon           | 3     | 0%  | 0%   | 33%   | 33%   | 33%  | 0%            |
| Canada             | 4,669 | 1%  | 7%   | 7%    | 48%   | 37%  | 0%            |
| Colombia           | 1,612 | 0%  | 25%  | 10%   | 61%   | 4%   | 0%            |
| Costa Rica         | 87    | 0%  | 1%   | 8%    | 51%   | 38%  | 2%            |
| Cote d'Ivoire      | 3     | 0%  | 0%   | 0%    | 100%  | 0%   | 0%            |
| Czech Republic     | 837   | 1%  | 7%   | 6%    | 45%   | 41%  | 0%            |
| Dominican Republic | 27    | 0%  | 4%   | 11%   | 52%   | 19%  | 15%           |
| Egypt              | 562   | 7%  | 45%  | 3%    | 1%    | 2%   | 42%           |
| Estonia            | 111   | 2%  | 20%  | 10%   | 44%   | 16%  | 8%            |
| France             | 2,267 | 6%  | 15%  | 11%   | 38%   | 29%  | 0%            |
| Georgia            | 38    | 5%  | 29%  | 11%   | 32%   | 24%  | 0%            |
| Ghana              | 7     | 0%  | 100% | 0%    | 0%    | 0%   | 0%            |
| Greece             | 1,110 | 2%  | 13%  | 10%   | 40%   | 35%  | 0%            |
| Guatemala          | 23    | 4%  | 13%  | 13%   | 26%   | 17%  | 26%           |
| Honduras           | 17    | 18% | 18%  | 12%   | 41%   | 0%   | 12%           |
| Hong Kong (China)  | 2     | 0%  | 0%   | 0%    | 0%    | 100% | 0%            |
| Hungary            | 1,458 | 1%  | 5%   | 6%    | 43%   | 42%  | 2%            |
| India              | 563   | 1%  | 13%  | 13%   | 47%   | 15%  | 10%           |

|                    | VVD   | 0-4  | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|--------------------|-------|------|------|-------|-------|-----|---------------|
| Indonesia          | 9     | 0%   | 22%  | 11%   | 44%   | 0%  | 22%           |
| Iran               | 1,585 | 3%   | 17%  | 11%   | 53%   | 15% | 0%            |
| Iraq               | 401   | 17%  | 27%  | 39%   | 14%   | 3%  | 0%            |
| Ireland            | 1,467 | 5%   | 18%  | 7%    | 46%   | 25% | 0%            |
| Jamaica            | 1     | 0%   | 0%   | 0%    | 100%  | 0%  | 0%            |
| Kenya              | 30    | 17%  | 27%  | 37%   | 17%   | 3%  | 0%            |
| Korea, Republic of | 129   | 1%   | 9%   | 9%    | 60%   | 21% | 0%            |
| Kyrgyzstan         | 16    | 6%   | 13%  | 31%   | 50%   | 0%  | 0%            |
| Lebanon            | 152   | 9%   | 18%  | 11%   | 49%   | 12% | 1%            |
| Madagascar         | 2     | 0%   | 0%   | 0%    | 100%  | 0%  | 0%            |
| Malaysia           | 50    | 8%   | 10%  | 14%   | 54%   | 14% | 0%            |
| Mali               | 14    | 21%  | 21%  | 21%   | 29%   | 7%  | 0%            |
| Mauritius          | 1     | 100% | 0%   | 0%    | 0%    | 0%  | 0%            |
| Mexico             | 306   | 2%   | 15%  | 12%   | 36%   | 8%  | 27%           |
| Moldova            | 5     | 0%   | 0%   | 0%    | 100%  | 0%  | 0%            |
| Mongolia           | 13    | 0%   | 23%  | 23%   | 38%   | 15% | 0%            |
| Myanmar            | 5     | 40%  | 60%  | 0%    | 0%    | 0%  | 0%            |
| Nepal              | 5     | 0%   | 0%   | 40%   | 40%   | 20% | 0%            |
| New Zealand        | 237   | 1%   | 8%   | 6%    | 36%   | 27% | 22%           |
| Nigeria            | 7     | 0%   | 57%  | 14%   | 14%   | 0%  | 14%           |
| Pakistan           | 250   | 4%   | 27%  | 14%   | 46%   | 2%  | 6%            |
| Panama             | 505   | 1%   | 20%  | 30%   | 40%   | 9%  | 0%            |
| Paraguay           | 1     | 0%   | 0%   | 0%    | 100%  | 0%  | 0%            |
| Philippines        | 39    | 0%   | 8%   | 5%    | 26%   | 5%  | 56%           |
| Poland             | 1,978 | 1%   | 15%  | 8%    | 50%   | 25% | 1%            |
| Portugal           | 51    | 2%   | 4%   | 4%    | 37%   | 49% | 4%            |
| Qatar              | 35    | 11%  | 26%  | 49%   | 9%    | 6%  | 0%            |
| Senegal            | 9     | 0%   | 33%  | 44%   | 11%   | 11% | 0%            |
| Serbia             | 300   | 1%   | 8%   | 6%    | 52%   | 33% | 0%            |
| Singapore          | 88    | 0%   | 13%  | 1%    | 43%   | 43% | 0%            |
| Slovak Republic    | 670   | 1%   | 6%   | 5%    | 55%   | 32% | 0%            |
| Slovenia           | 186   | 0%   | 6%   | 9%    | 53%   | 31% | 0%            |
| South Africa       | 643   | 0%   | 6%   | 8%    | 43%   | 40% | 4%            |
| Sri Lanka          | 49    | 12%  | 18%  | 4%    | 8%    | 10% | 47%           |

|                | VWD    | 0-4 | 5-13 | 14-18 | 19-44 | 45+ | Age Not Known |
|----------------|--------|-----|------|-------|-------|-----|---------------|
| Sudan          | 282    | 22% | 40%  | 14%   | 21%   | 4%  | 0%            |
| Sweden         | 200    | 3%  | 10%  | 6%    | 41%   | 40% | 1%            |
| Syria          | 98     | 13% | 31%  | 10%   | 39%   | 7%  | 0%            |
| Uganda         | 4      | 0%  | 75%  | 0%    | 0%    | 25% | 0%            |
| United Kingdom | 10,842 | 3%  | 11%  | 6%    | 41%   | 39% | 0%            |
| United States  | 11,336 | 6%  | 32%  | 22%   | 23%   | 17% | 0%            |
| Uruguay        | 258    | 0%  | 61%  | 1%    | 3%    | 1%  | 33%           |
| Uzbekistan     | 91     | 1%  | 10%  | 12%   | 63%   | 14% | 0%            |
| Venezuela      | 1,074  | 1%  | 12%  | 11%   | 38%   | 18% | 19%           |
| Vietnam        | 146    | 3%  | 21%  | 16%   | 43%   | 12% | 4%            |

## Table 14. HIV and HCV infection

(People currently living with HIV or HCV. 79 countries reported HIV and/or 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 |
| Albania            | 1                                      |     |                          | 18  |      |                          |  |     |                          |
| Algeria            | 2                                      | 0   | 0                        | 24  | 15   | 2                        | 9  | 7   | 0                        |
| Argentina          | 56                                     | 0   |                          | 605   | 20   |                          |  |     |                          |
| Armenia            |  | 1   |                          | 62  |      |                          | 3  |     |                          |
| Austria            | 48                                     |     |                          | 206   |      |                          |  |     |                          |
| Azerbaijan         |  |     |                          | 576   | 57   | 41                       | 21   | 57  | 19                       |
| Barbados           | 0                                      | 0   | 0                        | 2   | 0    | 0                        | 0  | 0   | 0                        |
| Belarus            | 0                                      | 0   | 0                        |   |      |                          |  |     |                          |
| Botswana           | 1                                      |     |                          |   |      |                          |  |     |                          |
| Burkina Faso       | 0                                      |     |                          |   |      |                          |  |     |                          |
| Cameroon           | 0                                      | 0   | 0                        | 0   | 0    | 0                        | 0  | 0   | 0                        |
| Chile              | 5                                      | 0   | 0                        |   |      |                          |  |     |                          |
| Colombia           | 12                                     | 2   | 0                        | 192   | 50   | 6                        | 50   | 6   | 2                        |
| Costa Rica         | 11                                     | 0   | 0                        | 48  | 0    | 1                        | 5  | 0   | 0                        |
| Cote d'Ivoire      | 1                                      | 0   | 0                        | 1   | 0    | 0                        | 0  | 0   | 0                        |
| Czech Republic     | 3                                      | 0   | 0                        | 207   | 3    | 0                        | 66   | 2   | 0                        |
| Dominican Republic | 0                                      | 0   | 0                        | 29  |      | 4                        | 27   |     | 4                        |
| Ecuador            | 10                                     | 10  |                          | 18  | 3    |                          |  |     |                          |
| Estonia            | 1                                      | 0   | 0                        | 28  | 1    |                          |  |     |                          |
| France             | 528                                    | 16  | 3                        | 2,018   | 174  | 48                       | 79   | 4   | 3                        |
| Georgia            |  |     |                          | 140   |      |                          | 134  |     |                          |
| Germany            | 367                                    |     |                          |   |      |                          |  |     |                          |
| Ghana              | 0                                      | 0   | 0                        | 0   | 0    | 0                        | 0  | 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 |
| Greece             | 50                                     | 2   | 0                        | 271   | 26   | 0                        | 59   | 6   | 0                        |
| Guatemala          |  |     |                          | 1   | 1    | 1                        |  |     |                          |
| Honduras           |  | 1   |                          |   |      |                          |  |     |                          |
| Hong Kong (China)  |  |     |                          |   |      |                          | 3  | 0   | 0                        |
| Hungary            | 10                                     | 0   | 0                        | 400   | 110  | 0                        |  |     |                          |
| India              | 110                                    |     |                          |   |      |                          |  |     |                          |
| Indonesia          |  |     |                          | 52  |      |                          |  |     |                          |
| Iran               | 27                                     | 0   | 4                        | 670   | 56   | 83                       | 156  | 10  | 21                       |
| Iraq               | 0                                      | 0   | 0                        | 300   | 63   | 5                        |  | 1   |                          |
| Ireland            | 37                                     |     |                          | 130   |      |                          | 3  |     |                          |
| Israel             | 24                                     | 0   | 0                        |   |      |                          |  |     |                          |
| Italy              | 194                                    | 10  | 6                        | 1,382   | 109  | 82                       |  |     |                          |
| Japan              | 878                                    | 9   | 3                        |   |      |                          |  |     |                          |
| Jordan             | 2                                      |     |                          | 46  |      |                          |  |     |                          |
| Kenya              | 23                                     | 2   | 0                        |   |      |                          |  |     |                          |
| Korea, Republic of | 18                                     |     |                          | 558   |      |                          | 93   |     |                          |
| Kyrgyzstan         | 0                                      | 0   | 0                        | 30  |      |                          | 5  |     |                          |
| Lebanon            | 0                                      | 0   | 0                        | 6   | 0    | 0                        | 1  | 0   | 0                        |
| Lesotho            | 0                                      |     |                          |   |      |                          |  |     |                          |
| Madagascar         | 0                                      | 0   | 0                        | 1   | 0    | 0                        | 0  | 0   | 0                        |
| Malaysia           | 3                                      | 0   | 0                        | 400   | 0    | 0                        | 220  | 0   | 0                        |
| Maldives           | 0                                      | 0   | 0                        | 0   | 0    | 0                        | 0  | 0   | 0                        |
| Mauritius          | 0                                      | 0   | 0                        | 8   | 0    | 0                        | 8  | 0   | 0                        |
| Mexico             | 46                                     | 3   | 0                        | 266   | 6    | 0                        |  |     |                          |
| Moldova            | 0                                      | 0   | 0                        |   |      |                          |  |     |                          |
| Mozambique         | 1                                      |     |                          | 1   |      |                          |  |     |                          |
| Myanmar            | 0                                      | 0   |                          | 3   | 0    |                          | 1  |     |                          |
| Nepal              | 1                                      |     |                          | 9   |      |                          |  |     |                          |
| New Zealand        | 6                                      | 0   | 0                        | 32  | 2    | 0                        | 4  | 1   | 0                        |
| Nicaragua          |  |     |                          | 23  |      |                          |  |     |                          |



|                 | 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 |
| Norway          | 6                                      | 0         | 0                        |   |              |                          |  |            |                          |
| Pakistan        | 13                                     | 1         | 2                        | 244   | 52           | 11                       | 192  | 42         | 8                        |
| Panama          | 0                                      | 0         | 0                        | 23  | 5            | 0                        | 20   | 5          | 0                        |
| Paraguay        | 1                                      |           |                          | 1   |              |                          | 1  |            |                          |
| Qatar           | 0                                      | 0         | 0                        | 0   | 0            | 0                        | 0  | 0          | 0                        |
| Senegal         | 0                                      | 0         | 0                        | 0   | 0            | 0                        | 0  | 0          | 0                        |
| Serbia          | 7                                      | 2         | 0                        | 116   | 12           | 1                        |  |            |                          |
| Singapore       | 0                                      | 0         | 0                        | 69  | 2            | 0                        | 0  | 0          | 0                        |
| Slovak Republic | 0                                      | 0         | 0                        | 130   | 22           | 16                       | 22   | 2          | 0                        |
| Slovenia        | 7                                      | 0         | 0                        | 96  | 6            | 3                        | 0  | 0          | 0                        |
| South Africa    | 75                                     | 3         | 0                        | 217   | 4            | 2                        | 17   | 4          | 2                        |
| Sri Lanka       |  |           |                          | 1   |              |                          |  |            |                          |
| Sudan           | 2                                      | 1         |                          | 41  |              |                          |  |            |                          |
| Sweden          | 15                                     |           |                          |   |              |                          |  |            |                          |
| Switzerland     | 17                                     |           |                          | 114   |              |                          |  |            |                          |
| Syria           | 0                                      | 0         | 0                        | 71  | 6            | 0                        |  |            |                          |
| Thailand        | 5                                      | 0         | 0                        |   |              |                          |  |            |                          |
| Togo            | 0                                      |           |                          |   |              |                          |  |            |                          |
| Uganda          | 1                                      |           |                          | 1   |              |                          |  |            |                          |
| United Kingdom  | 276                                    | 4         | 0                        | 1,230   | 130          | 17                       |  |            |                          |
| United States   | 961                                    | 14        | 5                        | 2,047   | 108          | 26                       |  |            |                          |
| Uruguay         | 0                                      | 0         | 0                        | 6   | 0            | 0                        | 6  | 0          | 0                        |
| Uzbekistan      | 10                                     |           |                          | 186   | 9            |                          |  |            |                          |
| Venezuela       | 84                                     | 9         | 1                        | 320   | 24           |                          | 60   | 8          |                          |
| Vietnam         | 4                                      | 0         | 0                        | 226   | 6            | 25                       | 0  | 0          | 0                        |
| Zambia          | 1                                      | 0         | 0                        | 0   | 0            | 0                        | 0  | 0          | 0                        |
| <b>Total</b>    | <b>3,961</b>                           | <b>90</b> | <b>24</b>                | <b>13,902</b>                                     | <b>1,082</b> | <b>374</b>               | <b>1,265</b>   | <b>155</b> | <b>59</b>                |

\* 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

(86 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 |
|--------------------|---------------------------------|---------------------|--------------------------------|---------------------|
| Algeria            | 100%                            | Estimate            | 100%                           | Estimate            |
| Argentina          | 75%                             | Estimate            | 5%                             | Estimate            |
| Armenia            | 50%                             | Estimate            | 25%                            | Estimate            |
| Australia          | 88%                             | Estimate            | 71%                            | Estimate            |
| Austria            | 89%                             | Precise             | 68%                            | Precise             |
| Azerbaijan         | 20%                             | Precise             |                                |                     |
| Barbados           | 75%                             | Precise             | 100%                           | Precise             |
| Belgium            | 90%                             | Estimate            | 75%                            | Estimate            |
| Brazil             | 92%                             | Precise             | 41%                            | Precise             |
| Burkina Faso       | 18%                             | Precise             | 9%                             | Precise             |
| Cambodia           | 50%                             | Estimate            |                                |                     |
| Cameroon           | 5%                              | Precise             | 0%                             | Precise             |
| Chile              | 100%                            | Estimate            | 50%                            | Estimate            |
| Colombia           | 90%                             | Precise             | 80%                            | Precise             |
| Costa Rica         | 58%                             | Precise             | 15%                            | Precise             |
| Cote d'Ivoire      | 15%                             | Precise             | 0%                             | Precise             |
| Czech Republic     | 93%                             | Precise             | 58%                            | Precise             |
| Dominican Republic | 15%                             | Precise             | 0%                             | Precise             |
| Ecuador            | 100%                            | Estimate            | 80%                            | Estimate            |
| Egypt              | 100%                            | Precise             | 0%                             | Precise             |
| Eritrea            | 78%                             | Precise             | 37%                            | Precise             |
| Estonia            | 100%                            | Precise             | 28%                            | Precise             |
| Ethiopia           | 0%                              | Precise             | 0%                             | Precise             |
| Finland            | 90%                             | Estimate            |                                |                     |
| France             | 79%                             | Precise             | 55%                            | Precise             |
| Georgia            | 32%                             | Estimate            | 18%                            | Estimate            |
| Germany            | 100%                            | Estimate            |                                |                     |
| Ghana              | 36%                             | Estimate            |                                |                     |
| Greece             | 90%                             | Precise             | 36%                            | Estimate            |
| Guatemala          | 17%                             | Estimate            |                                |                     |

|                    | Percent under 18 on prophylaxis | Precise or estimate | Percent over 18 on prophylaxis | Precise or estimate |
|--------------------|---------------------------------|---------------------|--------------------------------|---------------------|
| Hungary            | 100%                            | Precise             | 70%                            | Estimate            |
| Indonesia          | 0%                              | Precise             | 0%                             | Precise             |
| Iran               | 60%                             | Estimate            | 0%                             | Precise             |
| Iraq               | 80%                             | Estimate            | 10%                            | Estimate            |
| Ireland            | 100%                            | Estimate            | 85%                            | Estimate            |
| Israel             | 90%                             | Estimate            | 55%                            | Estimate            |
| Jamaica            | 0%                              | Precise             | 0%                             | Precise             |
| Japan              | 90%                             | Estimate            | 78%                            | Estimate            |
| Jordan             | 40%                             | Estimate            | 0%                             | Estimate            |
| Kenya              | 14%                             | Precise             | 4%                             | Precise             |
| Korea, Republic of | 88%                             | Estimate            | 48%                            | Estimate            |
| Kyrgyzstan         | 0%                              | Precise             | 0%                             | Precise             |
| Lebanon            | 45%                             | Estimate            | 30%                            | Estimate            |
| Lesotho            | 0%                              | Precise             | 0%                             | Precise             |
| Lithuania          | 100%                            | Precise             | 38%                            | Estimate            |
| Madagascar         | 20%                             | Estimate            | 10%                            | Estimate            |
| Malawi             | 3%                              | Estimate            | 5%                             | Estimate            |
| Malaysia           | 90%                             | Estimate            | 70%                            | Estimate            |
| Maldives           | 10%                             | Estimate            |                                |                     |
| Mali               | 98%                             | Estimate            | 75%                            | Estimate            |
| Mauritius          | 100%                            | Precise             | 82%                            | Precise             |
| Mozambique         | 2%                              | Estimate            | 70%                            | Estimate            |
| Myanmar            | 11%                             | Estimate            |                                |                     |
| Netherlands        | 100%                            | Precise             | 100%                           | Estimate            |
| New Zealand        | 100%                            | Estimate            | 50%                            | Estimate            |
| Nicaragua          | 0%                              | Precise             | 0%                             | Precise             |
| Nigeria            | 11%                             | Precise             | 3%                             | Precise             |
| Norway             | 95%                             | Estimate            | 70%                            | Estimate            |
| Pakistan           | 60%                             | Precise             | 5%                             | Estimate            |
| Panama             | 100%                            | Precise             | 100%                           | Precise             |
| Paraguay           | 5%                              | Precise             | 1%                             | Precise             |
| Philippines        | 1%                              | Estimate            | 1%                             | Estimate            |
| Poland             | 100%                            | Precise             |                                |                     |
| Qatar              | 50%                             | Precise             | 50%                            | Precise             |
| Russia             | 90%                             | Estimate            | 65%                            | Estimate            |
| Senegal            | 11%                             | Estimate            | 0%                             | Precise             |



|                 | Percent under 18 on prophylaxis | Precise or estimate | Percent over 18 on prophylaxis | Precise or estimate |
|-----------------|---------------------------------|---------------------|--------------------------------|---------------------|
| Serbia          | 90%                             | Estimate            | 35%                            | Estimate            |
| Singapore       | 92%                             | Precise             | 59%                            | Precise             |
| Slovak Republic | 95%                             | Precise             | 42%                            | Estimate            |
| Slovenia        | 77%                             | Precise             | 64%                            | Precise             |
| South Africa    | 35%                             | Estimate            | 25%                            | Estimate            |
| Sri Lanka       | 23%                             | Precise             | 10%                            | Precise             |
| Sweden          | 100%                            | Estimate            | 90%                            | Estimate            |
| Syria           | 0%                              | Estimate            | 0%                             | Estimate            |
| Tanzania        | 0%                              | Precise             | 0%                             | Precise             |
| Thailand        | 20%                             | Estimate            | 0%                             | Estimate            |
| Togo            | 0%                              | Estimate            | 0%                             | Estimate            |
| Tunisia         | 25%                             | Estimate            |                                |                     |
| Uganda          | 1%                              | Precise             | 1%                             | Precise             |
| United Kingdom  | 95%                             | Estimate            | 80%                            | Estimate            |
| Uruguay         | 50%                             | Estimate            | 10%                            | Estimate            |
| Uzbekistan      | 0%                              | Precise             | 0%                             | Precise             |
| Venezuela       | 50%                             | Estimate            | 30%                            | Estimate            |
| Vietnam         | 10%                             | Estimate            | 4%                             | Estimate            |
| Zambia          | 29%                             | Precise             | 29%                            | Precise             |
| Zimbabwe        | 5%                              | Estimate            | 5%                             | Estimate            |

## Table 16. Use of Factor Concentrates in 2017: Factor VIII

(93 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 certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2017 while others report the amount purchased. 2017 is the first year where data on the purchase of extended half-life products is reported. Factor VIII IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. 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 provided humanitarian aid products.

|                | Factor VIII Total IU | FVIII Plasma Derived | Factor VIII Recombinant | Factor VIII Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor VIII Humanitarian Aid Total | Factor VIII WFH Humanitarian Aid - Conventional | Factor VIII WFH Humanitarian Aid - Extended half-life | Factor VIII Per Capita | FVIII Per Capital Without Humanitarian Aid |
|----------------|----------------------|----------------------|-------------------------|---|------------------------------|---------------------------|----------------------------------|------------------------------------|---|---|------------------------|--|
| Albania        | 7,500,000            | No data              | No data                 | No data                                     |                              |                           |                                  | 3,000,000                          |   |   | 2.610                  | 1.566                                      |
| Algeria        | 82,472,000           | No data              | 44,525,250              | No data                                     |                              | 54                        |                                  | No data                            |   |   | 1.996                  | 1.996                                      |
| Argentina      | 211,250,000          | 129,200,000          | 78,800,000              | 0   | 62                           | 38                        | 0                                | 3,250,000                          |   |   | 4.772                  | 4.698                                      |
| Armenia        | 1,850,000            | 500,000              | No data                 | No data                                     | 100                          |                           |                                  | 1,350,000                          |   | 1,350,000   | 0.631                  | 0.171                                      |
| Australia      | 167,410,310          | 19,704,008           | 147,706,302             | 0   | 12                           | 88                        | 0                                | 0                                  |   |   | 6.806                  | 6.806                                      |
| Azerbaijan     | 17,000,000           | 17,000,000           | No data                 | No data                                     | 100                          |                           |                                  | No data                            |   |   | 1.724                  | 1.724                                      |
| Bangladesh     | 4,086,500            | No data              | No data                 | No data                                     |                              |                           |                                  | 4,086,500                          | 649,000   | 3,437,500   | 0.025                  |  |
| Barbados       | 195,000              | 175,000              | No data                 | No data                                     | 100                          |                           |                                  | 20,000                             |   |   | 0.682                  | 0.612                                      |
| Belize         | 288,190              | No data              | No data                 | No data                                     |                              |                           |                                  | 288,190                            | 110,000   | 75,000  | 0.769                  |  |
| Brazil         | 787,894,500          | 214,420,750          | 573,473,750             | No data                                     | 27                           | 73                        |                                  | 0                                  |   |   | 3.765                  | 3.765                                      |
| Burkina Faso   | 274,500              | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 274,500                            | 124,500   | 150,000   | 0.014                  | 0.000                                      |
| Cambodia       | 200,000              | No data              | No data                 | No data                                     |                              |                           |                                  | 200,000                            | 200,000   |   | 0.012                  |  |
| Cameroon       | 900,000              | No data              | No data                 | No data                                     |                              |                           |                                  | 900,000                            | 350,000   | 550,000   | 0.037                  |  |
| Canada         | 288,533,861          | 50,181,534           | 180,166,321             | 58,186,006                                  | 17                           | 62                        | 20                               | 0                                  |   |   | 7.860                  | 7.860                                      |
| Chile          | 57,000,000           | 57,000,000           | 0                       | 0   | 100                          | 0                         | 0                                | 0                                  |   |   | 3.157                  | 3.157                                      |
| Colombia       | 225,454,500          | 90,784,000           | 134,662,000             | 0   | 40                           | 60                        | 0                                | 8,500                              |   |   | 4.595                  | 4.595                                      |
| Costa Rica     | 16,057,500           | 16,057,500           | 0                       | 0   | 100                          | 0                         | 0                                | No data                            |   |   | 3.273                  | 3.273                                      |
| Cote d'Ivoire  | 699,000              | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 699,000                            | 299,000   | 350,000   | 0.029                  | 0.000                                      |
| Czech Republic | 65,722,514           | 29,051,202           | 34,856,912              | 1,814,400                                   | 44                           | 53                        | 3                                | 0                                  |   |   | 6.205                  | 6.205                                      |

|                      | Factor VIII Total IU | FVIII Plasma Derived | Factor VIII Recombinant | Factor VIII Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor VIII Humanitarian Aid Total | Factor VIII WFH Humanitarian Aid - Conventional | Factor VIII WFH Humanitarian Aid - Extended half-life | Factor VIII Per Capita | FVIII Per Capital Without Humanitarian Aid |
|----------------------|----------------------|----------------------|-------------------------|---|------------------------------|---------------------------|----------------------------------|------------------------------------|---|---|------------------------|--|
| Dominican Republic   | 1,650,000            | No data              | No data                 | No data                                     |                              |                           |                                  | 1,650,000                          | 200,000   | 1,450,000   | 0.153                  |  |
| Ecuador <sup>§</sup> | 35,014,000           | 27,941,000           | 6,973,000               | No data                                     | 80                           | 20                        |                                  | 10,000                             | 10,000  |   | 2.101                  | 2.100                                      |
| Egypt                | 31,180,000           | 15,830,000           | 500,000                 | 7,425,000                                   | 67                           | 2                         | 31                               | 7,425,000                          |   | 3,100,000   | 0.320                  | 0.244                                      |
| Eritrea              | 500,000              | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 500,000                            | 106,000   | 387,500   | 0.085                  | 0.000                                      |
| Estonia              | 6,331,050            | 4,420,300            | 1,910,750               | No data                                     | 70                           | 30                        |                                  | No data                            |   |   | 4.813                  | 4.813                                      |
| Ethiopia             | 2,710,500            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 2,710,500                          | 548,000   | 2,162,500   | 0.026                  | 0.000                                      |
| Finland              | 44,035,250           | 5,828,000            | 38,207,250              | No data                                     | 13                           | 87                        |                                  | 0                                  |   |   | 7.990                  | 7.990                                      |
| France               | 472,856,500          | 76,446,250           | 296,845,000             | 99,565,250                                  | 16                           | 63                        | 21                               | 0                                  |   |   | 7.045                  | 7.045                                      |
| Georgia              | 8,500,000            | 8,500,000            | No data                 | No data                                     | 100                          |                           |                                  | No data                            |   |   | 2.287                  | 2.287                                      |
| Germany              | 660,218,921          | 238,588,600          | 421,630,321             | No data                                     | 36                           | 64                        |                                  | 0                                  |   |   | 7.984                  | 7.984                                      |
| Ghana                | 403,000              | No data              | No data                 | No data                                     |                              |                           |                                  | 403,000                            | 403,000   |   | 0.014                  | 0.000                                      |
| Greece               | 47,030,950           | 6,679,200            | 38,223,700              | 2,128,050                                   | 14                           | 81                        | 5                                | 0                                  |   |   | 4.371                  | 4.371                                      |
| Guatemala            | 47,181,690           | 11,000,000           | 36,000,000              | No data                                     | 23                           | 77                        |                                  | 181,690                            |   |   | 2.790                  | 2.779                                      |
| Guyana               | 150,000              | No data              | No data                 | No data                                     |                              |                           |                                  | 150,000                            |   |   | 0.193                  |  |
| Honduras             | 12,904,500           | 11,929,500           | No data                 | No data                                     | 100                          |                           |                                  | 975,000                            | 575,000   | 400,000   | 1.393                  | 1.288                                      |
| Hungary              | 124,660,500          | 76,851,000           | 47,809,500              | 0   | 62                           | 38                        | 0                                | No data                            |   |   | 12.745                 | 12.745                                     |
| India                | 208,031,266          | 122,400,000          | No data                 | 38,848,485                                  | 76                           |                           | 24                               | 46,782,781                         | 19,582,781                                      | 27,200,000  | 0.155                  | 0.120                                      |
| Indonesia            | 2,707,870            | No data              | 0                       | 0   |                              |                           |                                  | 2,707,870                          | 257,870   | 2,450,000   | 0.010                  |  |
| Iran                 | 158,029,050          | 86,916,750           | 71,112,300              | 0   | 55                           | 45                        | 0                                | 0                                  |   |   | 1.947                  | 1.947                                      |
| Iraq                 | 42,000,000           | 0                    | 42,000,000              | No data                                     | 0                            | 100                       |                                  | 0                                  |   |   | 1.097                  | 1.097                                      |
| Ireland              | 52,496,750           | 3,906,000            | 39,758,750              | 8,832,000                                   | 7                            | 76                        | 17                               | 0                                  |   |   | 10.906                 | 10.906                                     |
| Italy                | 507,500,000          | No data              | No data                 | No data                                     |                              |                           |                                  | No data                            |   |   | 8.381                  | 8.381                                      |
| Jamaica              | 1,105,200            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 1,105,200                          | 367,700   | 737,500   | 0.382                  | 0.000                                      |
| Japan                | 881,200,000          | 79,100,000           | 802,100,000             | No data                                     | 9                            | 91                        |                                  | 0                                  |   |   | 6.950                  | 6.950                                      |
| Jordan               | 7,365,830            | 3,500,000            | 1,500,000               | 0   | 70                           | 30                        | 0                                | 2,365,830                          | 65,830  | 2,300,000   | 0.759                  | 0.515                                      |
| Kenya                | 4,100,000            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 4,100,000                          |   | 937,500   | 0.082                  | 0.000                                      |
| Korea, Republic of   | 254,792,000          | 57,695,000           | 197,097,000             | No data                                     | 23                           | 77                        |                                  | No data                            |   |   | 4.951                  | 4.951                                      |
| Kyrgyzstan           | 4,515,500            | 497,500              | 1,198,000               | 0   | 29                           | 71                        | 0                                | 2,820,000                          | 645,000   | 2,175,000   | 0.728                  | 0.273                                      |
| Latvia <sup>§</sup>  | 8,232,750            | 5,971,000            | 2,261,750               | 0   | 73                           | 27                        | 0                                | 0                                  |   |   | 4.242                  | 4.242                                      |
| Lebanon              | 1,100,199            | No data              | No data                 | No data                                     |                              |                           |                                  | 1,100,199                          | 1,100,199                                       |   | 0.181                  |  |
| Lithuania            | 18,964,250           | 10,911,500           | 8,052,750               | No data                                     | 58                           | 42                        |                                  | No data                            |   |   | 6.707                  | 6.707                                      |
| Madagascar           | 891,000              | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 891,000                            | 641,000   | 250,000   | 0.035                  | 0.000                                      |

|                 | Factor VIII Total IU | FVIII Plasma Derived | Factor VIII Recombinant | Factor VIII Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor VIII Humanitarian Aid Total | Factor VIII WFH Humanitarian Aid - Conventional | Factor VIII WFH Humanitarian Aid - Extended half-life | Factor VIII Per Capita | FVIII Per Capital Without Humanitarian Aid |
|-----------------|----------------------|----------------------|-------------------------|---|------------------------------|---------------------------|----------------------------------|------------------------------------|---|---|------------------------|--|
| Malawi          | 352,900              | No data              | 0                       | 0   |                              | 0                         | 0                                | 352,900                            | 152,900   | 200,000   | 0.019                  | 0.000                                      |
| Malaysia        | 34,296,500           | 27,096,500           | 7,200,000               | 0   | 79                           | 21                        | 0                                | 0                                  |   |   | 1.084                  | 1.084                                      |
| Maldives        | 312,500              | No data              | No data                 | No data                                     |                              |                           |                                  | 312,500                            |   | 312,500   | 0.716                  |  |
| Mali            | 1,020,880            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 1,020,880                          | 283,380   | 737,500   | 0.055                  | 0.000                                      |
| Mauritius       | 2,743,500            | 2,544,500            | 0                       | 0   | 100                          | 0                         | 0                                | 199,000                            | 199,000   |   | 2.169                  | 2.012                                      |
| Moldova         | 4,000,000            | 4,000,000            | 0                       | 0   | 100                          | 0                         | 0                                | 0                                  |   |   | 1.127                  | 1.127                                      |
| Mongolia        | 2,011,830            | No data              | 1,174,000               | No data                                     |                              | 100                       |                                  | 837,830                            | 200,000   | 537,500   | 0.654                  | 0.382                                      |
| Myanmar         | 2,801,400            | No data              | 1,400                   | No data                                     |                              | 100                       |                                  | 2,800,000                          | 1,344,000                                       | 1,250,000   | 0.052                  | 0.000                                      |
| Nepal           | 677,400              | No data              | No data                 | No data                                     |                              |                           |                                  | 677,400                            | 202,400   | 475,000   | 0.023                  |  |
| Nicaragua       | 7,120,000            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 7,120,000                          | 102,000   | 700,000   | 1.145                  | 0.000                                      |
| Nigeria         | 3,007,640            | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 3,007,640                          | 579,820   | 2,375,000   | 0.016                  | 0.000                                      |
| Norway          | 35,530,000           | 2,732,000            | 31,867,000              | 931,000                                     | 8                            | 90                        | 3                                | 0                                  |   |   | 6.726                  | 6.726                                      |
| Pakistan        | 10,168,750           | 743,750              | 0                       | 0   | 100                          | 0                         | 0                                | 9,425,000                          | 500,000   | 8,925,000   | 0.052                  | 0.004                                      |
| Panama          | 10,781,750           | 10,394,250           | 387,500                 | 0   | 96                           | 4                         | 0                                | No data                            |   |   | 2.631                  | 2.631                                      |
| Paraguay        | 796,000              | No data              | No data                 | No data                                     |                              |                           |                                  | 700,000                            |   |   | 0.117                  | 0.014                                      |
| Philippines     | 10,129,600           | 2,300,000            | 0                       | 0   | 100                          | 0                         | 0                                | 7,829,600                          | 1,631,520                                       | 2,362,500   | 0.097                  | 0.022                                      |
| Poland          | 253,883,250          | 242,504,250          | 11,074,000              | 305,000                                     | 96                           | 4                         | 0                                | 0                                  |   |   | 6.685                  | 6.685                                      |
| Portugal        | 51,394,000           | 18,873,000           | 32,521,000              | No data                                     | 37                           | 63                        |                                  | No data                            |   |   | 4.993                  | 4.993                                      |
| Qatar           | 13,000,000           | 0                    | 12,856,000              | 144,000                                     | 0                            | 99                        | 1                                | 0                                  |   |   | 4.926                  | 4.926                                      |
| Russia          | 995,323,562          | 638,286,312          | 357,037,250             | 0   | 64                           | 36                        | 0                                | 0                                  |   |   | 6.888                  | 6.888                                      |
| Senegal         | 955,000              | 0                    | 0                       | 0   | 0                            | 0                         | 0                                | 955,000                            | 120,400   |   | 0.060                  | 0.000                                      |
| Serbia          | 26,424,750           | 11,747,000           | 11,677,750              | 0   | 50                           | 50                        | 0                                | 3,000,000                          |   |   | 3.763                  | 3.336                                      |
| Singapore       | 9,774,600            | 5,827,100            | 3,947,500               | 0   | 60                           | 40                        | 0                                | 0                                  |   |   | 1.742                  | 1.742                                      |
| Slovak Republic | 41,700,000           | 34,500,000           | 7,200,000               | 0   | 83                           | 17                        | 0                                | 0                                  |   |   | 7.666                  | 7.666                                      |
| Slovenia        | 17,427,500           | 2,566,000            | 14,147,500              | 714,000                                     | 15                           | 81                        | 4                                | 0                                  |   |   | 8.432                  | 8.432                                      |
| South Africa    | 61,614,300           | 59,306,800           | 2,307,500               | 0   | 96                           | 4                         | 0                                | 0                                  |   |   | 1.086                  | 1.086                                      |
| Sri Lanka       | 4,662,500            | No data              | No data                 | No data                                     |                              |                           |                                  | 4,662,500                          |   | 4,662,500   | 0.217                  |  |
| Sudan           | 8,662,500            | 7,162,500            | No data                 | No data                                     | 100                          |                           |                                  | 1,500,000                          | 1,500,000                                       |   | 0.214                  | 0.177                                      |
| Sweden          | 101,350,400          | 5,000,400            | 96,350,000              | No data                                     | 5                            | 95                        |                                  | 0                                  |   |   | 10.067                 | 10.067                                     |
| Syria           | 1,500,000            | No data              | 0                       | 0   |                              | 0                         | 0                                | 1,500,000                          | 1,500,000                                       |   | 0.082                  |  |
| Tanzania        | 994,940              | No data              | No data                 | No data                                     |                              |                           |                                  | 994,940                            | 44,940  | 950,000   | 0.017                  |  |
| Thailand        | 25,772,000           | 9,276,000            | 12,396,000              | No data                                     | 43                           | 57                        |                                  | 4,100,000                          |   | 4,100,000   | 0.373                  | 0.314                                      |
| Togo            | 50,000               | No data              | No data                 | No data                                     |                              |                           |                                  | 50,000                             | 50,000  |   | 0.006                  |  |

|                | Factor VIII Total IU  | FVIII Plasma Derived | Factor VIII Recombinant | Factor VIII Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor VIII Humanitarian Aid Total | Factor VIII WFH Humanitarian Aid - Conventional | Factor VIII WFH Humanitarian Aid - Extended half-life | Factor VIII Per Capita | FVIII Per Capital Without Humanitarian Aid |
|----------------|-----------------------|----------------------|-------------------------|---|------------------------------|---------------------------|----------------------------------|------------------------------------|---|---|------------------------|--|
| Uganda         | 1,074,267             | No data              | No data                 | No data                                     |                              |                           |                                  | 1,074,267                          | 924,267   | 150,000   | 0.025                  |  |
| Ukraine        | 50,880,500            | 33,786,750           | 17,093,750              | 0   | 66                           | 34                        | 0                                | 0                                  |   |   | 1.135                  | 1.135                                      |
| United Kingdom | 577,522,950           | 28,983,481           | 490,731,691             | 57,807,778                                  | 5                            | 85                        | 10                               | 0                                  |   |   | 8.747                  | 8.747                                      |
| United States  | 3,116,000,000         | 349,000,000          | 2,014,000,000           | 753,000,000                                 | 11                           | 65                        | 24                               | No data                            |   |   | 9.567                  | 9.567                                      |
| Uruguay        | 9,100,000             | No data              | No data                 | 0   |                              |                           | 0                                | No data                            |   |   | 2.633                  | 2.633                                      |
| Uzbekistan     | 2,327,350             | No data              | No data                 | No data                                     |                              |                           |                                  | 2,325,000                          |   | 2,325,000   | 0.072                  | 0.000                                      |
| Venezuela      | 53,131,750            | 11,383,000           | 16,523,750              | 12,425,000                                  | 28                           | 41                        | 31                               | 12,800,000                         | 1,810,778                                       | 8,450,000   | 1.662                  | 1.261                                      |
| Vietnam        | 26,188,250            | 22,269,500           | 0                       | 0   | 100                          | 0                         | 0                                | 3,918,750                          |   | 2,100,000   | 0.274                  | 0.233                                      |
| Zambia         | 712,500               | No data              | No data                 | No data                                     |                              |                           |                                  | 712,500                            | 150,000   | 562,500   | 0.042                  |  |
| Zimbabwe       | 891,608               | No data              | No data                 | No data                                     |                              |                           |                                  | 891,608                            | 891,608   |   | 0.054                  |  |
| <b>TOTAL</b>   | <b>11,121,470,678</b> | <b>2,978,150,787</b> | <b>6,379,326,747</b>    | <b>1,042,125,969</b>                        |                              |                           |                                  | <b>162,722,075</b>                 | <b>38,421,893</b>                               | <b>90,287,500</b>                                     |                        |  |

<sup>§</sup> Data added/modified after final report; amounts not included in totals

## Table 17. Use of Factor Concentrates in 2017: Factor IX

(89 countries reported Factor IX data.)

The quantities of factor IX 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 certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2017 while others report the amount purchased. 2017 is the first year where data on the purchase of extended half-life products is reported. Factor IX Total IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. 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 provided humanitarian aid products.

|                      | Factor IX Total IU | Factor IX Plasma Derived | Factor IX Recombinant | Factor IX Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor IX Humanitarian Aid Total | Factor IX WFH Humanitarian Aid - Conventional | Factor IX WFH Humanitarian Aid - Extended half-life | Factor IX Per Capita | Factor IX Per Capital Without Humanitarian Aid |
|----------------------|--------------------|--------------------------|-----------------------|---|------------------------------|---------------------------|----------------------------------|----------------------------------|---|---|----------------------|--|
| Albania              | 400,000            | No data                  | No data               | No data                                   |                              |                           |                                  | No data                          |   |   | 0.139                | 13.921   |
| Algeria              | 19,800,000         | 19,800,000               | No data               | No data                                   | 100                          | 192                       |                                  | No data                          |   |   | 0.479                | 0.479  |
| Argentina            | 21,500,000         | 15,600,000               | 5,100,000             | 0   | 75                           | 25                        | 0                                | 800,000                          |   |   | 0.486                | 0.468  |
| Armenia              | 170,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 170,000                          |   | 25,000  | 0.058                | 0.000  |
| Australia            | 28,283,150         | 126,000                  | 28,157,150            | 0   | 0                            | 100                       | 0                                | 0                                |   |   | 1.150                | 1.150  |
| Azerbaijan           | 2,000,000          | 2,000,000                | No data               | No data                                   | 100                          |                           |                                  | No data                          |   |   | 0.203                | 0.203  |
| Bangladesh           | 1,050,000          | No data                  | No data               | No data                                   |                              |                           |                                  | 1,050,000                        |   | 1,050,000   | 0.006                | 0.000  |
| Barbados             | 160,000            | 150,000                  | No data               | No data                                   | 100                          |                           |                                  | 10,000                           |   |   | 0.560                | 0.525  |
| Belize               | 304,210            | No data                  | No data               | No data                                   |                              |                           |                                  | 304,210                          |   | 25,000  | 0.812                | 0.000  |
| Brazil               | 125,613,250        | 125,613,250              | No data               | No data                                   | 100                          |                           |                                  | 0                                |   |   | 0.600                | 0.600  |
| Burkina Faso         | 300,000            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 300,000                          |   | 300,000   | 0.016                | 0.000  |
| Cameroon             | 200,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 200,000                          |   | 200,000   | 0.008                | 0.000  |
| Canada               | 56,017,505         | 4,098,499                | 35,149,911            | 16,769,095                                | 7                            | 63                        | 30                               | 0                                |   |   | 1.526                | 1.526  |
| Chile                | 9,000,000          | 9,000,000                | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.498                | 0.498  |
| Colombia             | 33,641,500         | 14,600,000               | 19,033,000            | 0   | 43                           | 57                        | 0                                | 158,400                          |   |   | 0.689                | 0.685  |
| Costa Rica           | 3,484,000          | 3,484,000                | 0                     | 0   | 100                          | 0                         | 0                                | No data                          |   |   | 0.710                | 0.710  |
| Cote d'Ivoire        | 25,000             | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 25,000                           |   | 25,000  | 0.001                | 0.000  |
| Czech Republic       | 7,411,857          | 4,841,771                | 2,065,960             | 504,126                                   | 65                           | 28                        | 7                                | 0                                |   |   | 0.700                | 0.700  |
| Dominican Republic   | 375,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 375,000                          |   | 375,000   | 0.035                | 0.000  |
| Ecuador <sup>8</sup> | 2,916,500          | 2,916,500                | 0                     | No data                                   | 100                          | 0                         |                                  | 0                                |   |   | 0.175                | 0.175  |

|                     | Factor IX Total IU | Factor IX Plasma Derived | Factor IX Recombinant | Factor IX Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor IX Humanitarian Aid Total | Factor IX WFH Humanitarian Aid - Conventional | Factor IX WFH Humanitarian Aid - Extended half-life | Factor IX Per Capita | Factor IX Per Capital Without Humanitarian Aid |
|---------------------|--------------------|--------------------------|-----------------------|---|------------------------------|---------------------------|----------------------------------|----------------------------------|---|---|----------------------|--|
| Egypt               | 6,940,000          | No data                  | 190,000               | 3,375,000                                 |                              | 5                         | 95                               | 3,375,000                        |   | 2,575,000   | 0.071                | 0.037  |
| Eritrea             | 25,000             | No data                  | No data               | No data                                   |                              |                           |                                  | 25,000                           |   | 25,000  | 0.004                | 0.000  |
| Estonia             | 471,600            | 471,600                  | No data               | No data                                   | 100                          |                           |                                  | No data                          |   |   | 0.359                | 0.359  |
| Ethiopia            | 225,000            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 225,000                          |   | 225,000   | 0.002                | 0.000  |
| Finland             | 12,103,500         | 685,000                  | 11,418,500            | No data                                   | 6                            | 94                        |                                  | 0                                |   |   | 2.196                | 2.196  |
| France              | 81,365,000         | 27,908,500               | 53,456,500            | 0   | 34                           | 66                        | 0                                | 0                                |   |   | 1.212                | 1.212  |
| Georgia             | 1,500,000          | 1,500,000                | No data               | No data                                   | 100                          |                           |                                  | No data                          |   |   | 0.404                | 0.404  |
| Germany             | 68,381,100         | 38,011,800               | 30,369,300            | No data                                   | 56                           | 44                        |                                  | 0                                |   |   | 0.827                | 0.827  |
| Ghana               | 162,500            | No data                  | No data               | No data                                   |                              |                           |                                  | 162,500                          |   | 162,500   | 0.006                | 0.000  |
| Greece              | 5,613,000          | 217,500                  | 5,395,500             | 0   | 4                            | 96                        | 0                                | 0                                |   |   | 0.522                | 0.522  |
| Guatemala           | 2,088,500          | 2,082,500                | No data               | No data                                   | 100                          |                           |                                  | 6,000                            |   |   | 0.123                | 0.123  |
| Honduras            | 182,500            | 45,000                   | No data               | No data                                   | 100                          |                           |                                  | 137,500                          |   | 137,500   | 0.020                | 0.005  |
| India               | 50,300,000         | 42,500,000               | No data               | 750,000                                   | 98                           |                           | 2                                | 7,050,000                        |   | 7,050,000   | 0.038                | 0.032  |
| Indonesia           | 300,000            | No data                  | 0                     | 0   |                              | 0                         | 0                                | 300,000                          |   | 300,000   | 0.001                | 0.000  |
| Iran                | 11,355,000         | 11,355,000               | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.140                | 0.140  |
| Iraq                | 10,000,000         | 0                        | 10,000,000            | No data                                   | 0                            | 100                       |                                  | 0                                |   |   | 0.261                | 0.261  |
| Ireland             | 11,702,000         | 0                        | 4,417,250             | 7,284,750                                 | 0                            | 38                        | 62                               | 0                                |   |   | 2.431                | 2.431  |
| Italy               | 53,300,000         | No data                  | No data               | No data                                   |                              |                           |                                  | No data                          |   |   | 0.880                | 0.880  |
| Jamaica             | 78,000             | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 78,000                           |   | 25,000  | 0.027                | 0.000  |
| Japan               | 136,600,000        | 40,000,000               | 96,600,000            | No data                                   | 29                           | 71                        |                                  | 0                                |   |   | 1.077                | 1.077  |
| Jordan              | 1,701,480          | 1,000,000                | 500,000               | 0   | 67                           | 33                        | 0                                | 201,480                          | 101,480                                       | 100,000   | 0.175                | 0.155  |
| Kenya               | 250,000            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 250,000                          |   | 250,000   | 0.005                | 0.000  |
| Korea, Republic of  | 59,078,000         | 3,728,000                | 55,350,000            | No data                                   | 6                            | 94                        |                                  | No data                          |   |   | 1.148                | 1.148  |
| Kyrgyzstan          | 237,500            | 50,000                   | 62,500                | 0   | 44                           | 56                        | 0                                | 125,000                          |   | 125,000   | 0.038                | 0.018  |
| Latvia <sup>§</sup> | 713,500            | 713,500                  | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.368                | 0.368  |
| Lebanon             | 9,000              | No data                  | No data               | No data                                   |                              |                           |                                  | 9,000                            | 9,000   |   | 0.001                | 0.000  |
| Lithuania           | 3,758,100          | 3,758,100                | 0                     | 0   | 100                          | 0                         | 0                                | No data                          |   |   | 1.329                | 1.329  |
| Madagascar          | 337,500            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 337,500                          |   | 337,500   | 0.013                | 0.000  |
| Malawi              | 73,240             | No data                  | 0                     | 0   |                              | 0                         | 0                                | 73,240                           |   | 25,000  | 0.004                | 0.000  |
| Malaysia            | 6,572,050          | 6,572,050                | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.208                | 0.208  |
| Maldives            | 45,000             | No data                  | No data               | No data                                   |                              |                           |                                  | 45,000                           |   |   | 0.103                | 0.000  |
| Mali                | 0                  | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 0                                |   |   | 0.000                | 0.000  |

|                 | Factor IX Total IU | Factor IX Plasma Derived | Factor IX Recombinant | Factor IX Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor IX Humanitarian Aid Total | Factor IX WFH Humanitarian Aid - Conventional | Factor IX WFH Humanitarian Aid - Extended half-life | Factor IX Per Capita | Factor IX Per Capital Without Humanitarian Aid |
|-----------------|--------------------|--------------------------|-----------------------|---|------------------------------|---------------------------|----------------------------------|----------------------------------|---|---|----------------------|--|
| Mauritius       | 554,500            | 304,500                  | 0                     | 0   | 100                          | 0                         | 0                                | 250,000                          | 100,000                                       | 150,000   | 0.438                | 0.241  |
| Moldova         | 200,000            | 200,000                  | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.056                | 0.056  |
| Mongolia        | 689,500            | No data                  | 564,500               | No data                                   |                              | 100                       |                                  | 125,000                          |   | 125,000   | 0.224                | 0.184  |
| Myanmar         | 1,000,000          | No data                  | 0                     | 0   |                              | 0                         | 0                                | 1,000,000                        |   | 1,000,000   | 0.019                | 0.000  |
| Nepal           | 25,000             | No data                  | No data               | No data                                   |                              |                           |                                  | 25,000                           |   | 25,000  | 0.001                | 0.000  |
| Nicaragua       | 175,000            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 175,000                          |   | 175,000   | 0.028                | 0.000  |
| Nigeria         | 0                  | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 0                                |   |   | 0.000                | 0.000  |
| Norway          | 3,124,750          | 2,469,000                | 342,000               | 313,750                                   | 79                           | 11                        | 10                               | 0                                |   |   | 0.592                | 0.592  |
| Pakistan        | 2,707,000          | 232,000                  | 0                     | 0   | 100                          | 0                         | 0                                | 2,475,000                        |   | 2,475,000   | 0.014                | 0.001  |
| Panama          | 1,004,100          | 1,004,100                | 0                     | 0   | 100                          | 0                         | 0                                | No data                          |   |   | 0.245                | 0.245  |
| Paraguay        | 100,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 100,000                          |   |   | 0.015                | 0.000  |
| Philippines     | 599,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 599,000                          |   | 599,000   | 0.006                | 0.000  |
| Poland          | 37,637,900         | 35,829,900               | 1,808,000             | 0   | 95                           | 5                         | 0                                | 0                                |   |   | 0.991                | 0.991  |
| Portugal        | 7,718,250          | 3,750,000                | 3,968,250             | No data                                   | 49                           | 51                        |                                  | No data                          |   |   | 0.750                | 0.750  |
| Qatar           | 2,600,000          | 0                        | 2,520,000             | 80,000                                    | 0                            | 97                        | 3                                | 0                                |   |   | 0.985                | 0.985  |
| Russia          | 112,997,660        | 112,997,660              | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.782                | 0.782  |
| Senegal         | 108,000            | 0                        | 0                     | 0   | 0                            | 0                         | 0                                | 108,000                          | 16,000  |   | 0.007                | 0.000  |
| Serbia          | 3,114,000          | 1,837,000                | 1,277,000             | 0   | 59                           | 41                        | 0                                | 0                                |   |   | 0.443                | 0.443  |
| Singapore       | 2,222,500          | 663,500                  | 1,559,000             | 0   | 30                           | 70                        | 0                                | 0                                |   |   | 0.396                | 0.396  |
| Slovak Republic | 3,130,000          | 2,835,000                | 295,000               | 0   | 91                           | 9                         | 0                                | 0                                |   |   | 0.575                | 0.575  |
| Slovenia        | 1,152,500          | 432,500                  | 666,000               | 54,000                                    | 38                           | 58                        | 5                                | 0                                |   |   | 0.558                | 0.558  |
| South Africa    | 10,071,000         | 10,071,000               | 0                     | 0   | 100                          | 0                         | 0                                | 0                                |   |   | 0.178                | 0.178  |
| Sri Lanka       | 737,500            | No data                  | No data               | No data                                   |                              |                           |                                  | 737,500                          |   | 737,500   | 0.034                | 0.000  |
| Sudan           | 1,160,000          | 1,160,000                | No data               | No data                                   | 100                          |                           |                                  | No data                          |   |   | 0.029                | 0.029  |
| Sweden          | 20,453,300         | 8,139,800                | 12,313,500            | No data                                   | 40                           | 60                        |                                  | 0                                |   |   | 2.032                | 2.032  |
| Tanzania        | 400,000            | No data                  | No data               | No data                                   |                              |                           |                                  | 400,000                          |   | 400,000   | 0.007                | 0.000  |
| Thailand        | 2,676,000          | 2,676,000                | No data               | No data                                   | 100                          |                           |                                  | No data                          |   |   | 0.039                | 0.039  |
| Togo            | 2,922              | No data                  | No data               | No data                                   |                              |                           |                                  | 2,922                            | 2,922   |   | 0.000                | 0.000  |
| Uganda          | 237,500            | No data                  | No data               | No data                                   |                              |                           |                                  | 237,500                          |   | 237,500   | 0.006                | 0.000  |
| Ukraine         | 9,810,500          | 7,972,000                | 1,838,500             | 0   | 81                           | 19                        | 0                                | 0                                |   |   | 0.219                | 0.219  |
| United Kingdom  | 80,473,708         | 6,189,635                | 59,017,978            | 15,266,095                                | 8                            | 73                        | 19                               | 0                                |   |   | 1.219                | 1.219  |
| United States   | 523,000,000        | 64,000,000               | 285,000,000           | 174,000,000                               | 12                           | 54                        | 33                               | No data                          |   |   | 1.606                | 1.606  |
| Uruguay         | 600,000            | No data                  | 0                     | 0   |                              | 0                         | 0                                | No data                          |   |   | 0.174                | 0.174  |



|              | Factor IX Total IU   | Factor IX Plasma Derived | Factor IX Recombinant | Factor IX Recombinant, extended half-life | Total Percent Plasma Derived | Total Percent Recombinant | Total Percent Extended half-life | Factor IX Humanitarian Aid Total | Factor IX WFH Humanitarian Aid - Conventional | Factor IX WFH Humanitarian Aid - Extended half-life | Factor IX Per Capita | Factor IX Per Capital Without Humanitarian Aid |
|--------------|----------------------|--------------------------|-----------------------|---|------------------------------|---------------------------|----------------------------------|----------------------------------|---|---|----------------------|--|
| Uzbekistan   | 62,750               | No data                  | No data               | No data                                   |                              |                           |                                  | 62,500                           |   | 62,500  | 0.002                | 0.000  |
| Venezuela    | 6,100,000            | 500,000                  | No data               | 2,800,000                                 | 15                           |                           | 85                               | 2,800,000                        |   | 1,925,000   | 0.191                | 0.103  |
| Vietnam      | 3,290,150            | 2,804,900                | 0                     | 0   | 100                          | 0                         | 0                                | 485,250                          |   | 450,000   | 0.034                | 0.029  |
| Zambia       | 125,000              | No data                  | No data               | No data                                   |                              |                           |                                  | 125,000                          |   | 125,000   | 0.007                | 0.000  |
| Zimbabwe     | 70,000               | No data                  | No data               | No data                                   |                              |                           |                                  | 70,000                           |   |   | 0.004                | 0.000  |
| <b>TOTAL</b> | <b>1,674,911,682</b> | <b>645,558,715</b>       | <b>766,382,049</b>    | <b>221,196,816</b>                        |                              |                           |                                  | <b>25,570,502</b>                | <b>229,402</b>                                | <b>21,799,000</b>                                   |                      |  |

<sup>§</sup> Data added/modified after final report; amounts not included in totals

# Annual Global Survey 2017

## A. National Hemophilia Organization

|                         |                                  |
|-------------------------|----------------------------------|
| Organization name       |                                  |
| City                    |                                  |
| Country                 |                                  |
| Phone                   |                                  |
| E-mail                  |                                  |
| This form completed by: | First name<br>Last name<br>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?  | <b>Check one</b><br><input type="checkbox"/> Hemophilia Society and/or NMO registry or database<br><input type="checkbox"/> Hospital(s)/HTC(s) registry or database<br><input type="checkbox"/> Health Ministry registry or database<br><input type="checkbox"/> Other (please describe): |
| How often is your database updated?  | <input type="checkbox"/> Ongoing update (can be updated anytime)<br><input type="checkbox"/> Yearly update (the registry is updated once each year)<br><input type="checkbox"/> Other (please describe):  |
| Who updates the database?  | <input type="checkbox"/> Doctors update the database<br><input type="checkbox"/> Patient organization updates the database<br><input type="checkbox"/> Hospitals or clinics update the database<br><input type="checkbox"/> Other (please describe):                                      |
| Have all the identified patients in your country been included in this report? If not, please explain. | Yes <input type="checkbox"/> No <input type="checkbox"/><br>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)  |                              | <input type="checkbox"/>          |
| 2. Number of identified people with von Willebrand disease (VWD)  |                              | <input type="checkbox"/>          |
| 3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders. See question 6 for the list of specific disorders.) |                              | <input type="checkbox"/>          |
| Do you consider these numbers to be accurate?   | Yes <input type="checkbox"/> | Not sure <input type="checkbox"/> |

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

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## 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               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>            | <input type="checkbox"/> |

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

|  |                              |                                   |
|--|------------------------------|-----------------------------------|
| Do you consider these numbers to be accurate?  | Yes <input type="checkbox"/> | Not sure <input type="checkbox"/> |
| 5. Do you collect age data in a format that does not match question 4? (If you do collect age data in another format, please send it to the WFH in a separate attachment.) | Yes <input type="checkbox"/> |                                   |

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

## 6. Type of hereditary bleeding disorder

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

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

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

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

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

A woman who has  $\leq 40\%$  percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

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

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

# Annual Global Survey 2017

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

|  |   |  |                                  |
|--|---|--|----------------------------------|
| Factor level measurements <input type="checkbox"/> | Clinical diagnosis <input type="checkbox"/><br>(bleeding, family history) | Other <input type="checkbox"/><br>(please describe): | No data <input type="checkbox"/> |
|--|---|--|----------------------------------|

## How are patients with von Willebrand Disease classified?

|  |   |  |                                  |
|--|---|--|----------------------------------|
| Factor level measurements <input type="checkbox"/> | Severe bleeding symptoms <input type="checkbox"/> | Other <input type="checkbox"/><br>(please describe): | No data <input type="checkbox"/> |
|--|---|--|----------------------------------|

## 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 ≤40% 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<br>(factor level<br>above 5%) | Moderate<br>(factor level<br>1% to 5%) | Severe<br>(factor level<br>below 1%) | Severity<br>unknown | No Data                  |
|---------------------|------------------------------------|--|--------------------------------------|---------------------|--------------------------|
| Hemophilia A male   |                                    |  |                                      |                     | <input type="checkbox"/> |
| Hemophilia A female |                                    |  |                                      |                     | <input type="checkbox"/> |
| Hemophilia B male   |                                    |  |                                      |                     | <input type="checkbox"/> |
| Hemophilia B female |                                    |  |                                      |                     | <input type="checkbox"/> |

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

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

## 9. Number of severe VWD patients

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

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

## 10. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors in 2017. (Patients who do not respond to normal treatment.)

| Type of hemophilia | Total number with active<br>inhibitors | New cases of inhibitors in<br>2017 | No Data                  |
|--------------------|--|------------------------------------|--------------------------|
| Hemophilia A       |  |                                    | <input type="checkbox"/> |
| Hemophilia B       |  |                                    | <input type="checkbox"/> |

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

# Annual Global Survey 2017

## 11 A. Availability and usage of products to treat hemophilia

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

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

## 11 B. Availability and usage of non-factor products to treat hemophilia with inhibitors

| Treatment product     | Product is available     | Product is used          | Number of patients treated with product indicated | No data                  |
|-----------------------|--------------------------|--------------------------|---|--------------------------|
| Hemlibra (Emicizumab) | <input type="checkbox"/> | <input type="checkbox"/> |   | <input type="checkbox"/> |

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

## 12. Availability and usage of products to treat VWD

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

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

## 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 2017             |                                    |                        |                                     |

## 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 <sup>1</sup>         |                                    |                        |                                     |
| Total number of people with currently active hepatitis C <sup>2</sup> |                                    |                        |                                     |
| New hepatitis C infections in 2017                                    |                                    |                        |                                     |

<sup>1</sup>Hepatitis C antibody positive at any time

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

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## 15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2017)

| 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 <b>hemophilia treatment centres</b> are there in total in your country?   |  |
| How many of the <b>hemophilia treatment centres</b> you have indicated above have <b>direct access, within the same structure</b> , 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 (18 and under) <b>with severe hemophilia</b> are on prophylaxis? | Precise: <input type="checkbox"/><br>Estimate: <input type="checkbox"/> | Not known <input type="checkbox"/> |
| What percentage of adults (over age 18), <b>with severe hemophilia</b> are on prophylaxis?       | Precise: <input type="checkbox"/><br>Estimate: <input type="checkbox"/> | Not known <input type="checkbox"/> |
| 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 # of patients with inhibitors who received ITI in your country in the last year, and the number of new patients who started ITI during the last year. Please indicate if these #s are precise or an estimate.

|  |   |                                    |
|--|---|------------------------------------|
| 18. What is the total number of patients <b>with inhibitors</b> who received ITI during the last year? | Precise: <input type="checkbox"/><br>Estimate: <input type="checkbox"/> | Not known <input type="checkbox"/> |
| Of this total, how many were new patients who <b>started</b> ITI treatment during the last year?       | Precise: <input type="checkbox"/><br>Estimate: <input type="checkbox"/> | Not known <input type="checkbox"/> |

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

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## D. The Cost and Use of Factor Concentrates

| 19 A. Annual usage of purchased factor concentrates (please do not include donated factor)  | Factor VIII              | Not known                | Factor IX                | Not known                |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| <b>IN TOTAL</b> how many international units (IU) of factor concentrates were used in your country in 2017 (excluding donated factor)?  |                          | <input type="checkbox"/> |                          | <input type="checkbox"/> |
| <b>Plasma derived:</b> How many international units of <b>plasma-derived</b> concentrates were used in your country in 2017 (excluding donated factor)?   |                          | <input type="checkbox"/> |                          | <input type="checkbox"/> |
| <b>Recombinant, excluding extended half-life:</b> How many international units of <b>recombinant</b> concentrates ( <b>excluding extended half-life</b> ) were used in your country in 2017 (excluding donated factor)? |                          | <input type="checkbox"/> |                          | <input type="checkbox"/> |
| <b>Recombinant, extended half-life:</b> How many international units of <b>recombinant</b> concentrates, <b>extended half-life</b> were used in your country in 2017 (excluding donated factor)?                        |                          | <input type="checkbox"/> |                          | <input type="checkbox"/> |
| <b>If factor concentrates are purchased in your country but you are unable to report the quantities please check here:</b>  | <input type="checkbox"/> |                          | <input type="checkbox"/> |                          |

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

| 19 B. Annual usage of donated factor concentrates   | Factor VIII | Not known                | Factor IX | Not known                |
|---|-------------|--------------------------|-----------|--------------------------|
| How many international units of <b>donated factor</b> concentrates (plasma-derived or recombinant) from all sources, including <b>Humanitarian Aid</b> , were used in your country in 2017? |             | <input type="checkbox"/> |           | <input type="checkbox"/> |

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

**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 <input type="checkbox"/> Yes <input type="checkbox"/> | Tax rate: |
|-----------|--|-----------|

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

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## 20. Factor VIII Concentrates used in 2017

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in the currency used to purchase the product. Please indicate if this price includes tax.)

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



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

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

## 21. Factor IX Concentrates used in 2017

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

| Used                     | Brand Name             | Manufacturer                | Price per IU |
|--------------------------|------------------------|-----------------------------|--------------|
| <input type="checkbox"/> | Aimafix                | Kedrion                     |              |
| <input type="checkbox"/> | AlphaNine SD           | Grifols                     |              |
| <input type="checkbox"/> | Alprolix               | Biogen Idec                 |              |
| <input type="checkbox"/> | BeneFIX                | Wyeth                       |              |
| <input type="checkbox"/> | Berinin-P = Berinin HS | CSL Behring                 |              |
| <input type="checkbox"/> | BETAFACT               | LFB                         |              |
| <input type="checkbox"/> | Christmassin-M         | Benesis                     |              |
| <input type="checkbox"/> | Clotnine               | Hemarus                     |              |
| <input type="checkbox"/> | Factor IX Grifols      | Grifols                     |              |
| <input type="checkbox"/> | Faktor IX SDN          | Biotest                     |              |
| <input type="checkbox"/> | Fixnove                | Baxalta (now part of Shire) |              |
| <input type="checkbox"/> | Hemo-B-RAAS            | Shanghai RAAS               |              |
| <input type="checkbox"/> | Haemonine              | Biotest                     |              |
| <input type="checkbox"/> | Humafactor IX          | Kedrion                     |              |
| <input type="checkbox"/> | Immunine               | Baxalta (now part of Shire) |              |

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|                          |                |                             |  |
|--------------------------|----------------|-----------------------------|--|
| <input type="checkbox"/> | MonoFIX-VF     | CSL Bioplasma               |  |
| <input type="checkbox"/> | Mononine       | CSL Behring                 |  |
| <input type="checkbox"/> | Nanofix        | Octapharma                  |  |
| <input type="checkbox"/> | Nanotiv        | Octapharma                  |  |
| <input type="checkbox"/> | Nonafact       | Sanquin                     |  |
| <input type="checkbox"/> | Novact M       | Kaketsuken                  |  |
| <input type="checkbox"/> | Octafix        | Octapharma                  |  |
| <input type="checkbox"/> | Octanine F     | Octapharma                  |  |
| <input type="checkbox"/> | Replenine – VF | BioProducts Lab.            |  |
| <input type="checkbox"/> | Rixubis        | Baxalta (now part of Shire) |  |
| <input type="checkbox"/> | Other:         |                             |  |

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

## 22. Prothrombin Complex Concentrates used in 2017

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

| Used                     | Brand Name                 | Manufacturer                | Price per IU |
|--------------------------|----------------------------|-----------------------------|--------------|
| <input type="checkbox"/> | Bebulin VH                 | Baxalta (now part of Shire) |              |
| <input type="checkbox"/> | Beriplex P/N               | CSL Behring                 |              |
| <input type="checkbox"/> | Cofact                     | Sanquin                     |              |
| <input type="checkbox"/> | Facnyne                    | Greencross Corp             |              |
| <input type="checkbox"/> | Haemosolvex Factor IX      | National Bioproducts        |              |
| <input type="checkbox"/> | HT DEFIX                   | SNBTS                       |              |
| <input type="checkbox"/> | Kanokad Confidex           | LFB                         |              |
| <input type="checkbox"/> | KASKADIL                   | LFB                         |              |
| <input type="checkbox"/> | Octaplex                   | Octapharma                  |              |
| <input type="checkbox"/> | PPSB-HT                    | Nihon Pharmaceutical        |              |
| <input type="checkbox"/> | PPSB-human SD/Nano 300/600 | German Red Cross NSTOB      |              |
| <input type="checkbox"/> | Profiline SD               | Grifols                     |              |
| <input type="checkbox"/> | Proplex – T                | Baxalta (now part of Shire) |              |
| <input type="checkbox"/> | Prothrombinex PXT          | CSL Bioplasma               |              |
| <input type="checkbox"/> | Prothrombinex- VF          | CSL Bioplasma               |              |
| <input type="checkbox"/> | Prothromplex-T             | Baxalta (now part of Shire) |              |
| <input type="checkbox"/> | Prothrorraas               | Shanghai RAAS               |              |
| <input type="checkbox"/> | UMAN Complex D.I.          | Kedrion                     |              |
| <input type="checkbox"/> | Other:                     |                             |              |

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

## 23. Other Products used in 2017

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

| Used                     | Brand Name | Manufacturer | Price per IU |
|--------------------------|------------|--------------|--------------|
| <input type="checkbox"/> | Aryoseven  | Aryogen      |              |

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|                          |   |                             |                               |
|--------------------------|---|-----------------------------|-------------------------------|
| <input type="checkbox"/> | Byclot (1.5mg)                                      | Kaketusken                  |                               |
| <input type="checkbox"/> | Ceprothin   | Baxalta (now part of Shire) |                               |
| <input type="checkbox"/> | Clottafact Wilstart                                 | LFB                         |                               |
| <input type="checkbox"/> | Clottagen (fibrinogen)                              | LFB                         |                               |
| <input type="checkbox"/> | Coagil 7 (activated factor VII)                     | Pharmstandard               | Price per vial:<br>Vial size: |
| <input type="checkbox"/> | FACTEUR VII   | LFB                         |                               |
| <input type="checkbox"/> | Factor VII  | Baxalta (now part of Shire) |                               |
| <input type="checkbox"/> | Factor VII  | Bio Products                |                               |
| <input type="checkbox"/> | Factor X P Behring                                  | CSL Behring                 |                               |
| <input type="checkbox"/> | Factor XI   | Bio Products                |                               |
| <input type="checkbox"/> | FEIBA   | Baxalta (now part of Shire) |                               |
| <input type="checkbox"/> | Fibrinogen HT                                       | Benesis                     |                               |
| <input type="checkbox"/> | Fibrogammin P (=Fibrogammin HS) (Factor XIII)       | CSL Behring                 |                               |
| <input type="checkbox"/> | FIBRORAAS (fibrinogen)                              | Shanghai RAAS               |                               |
| <input type="checkbox"/> | Haemocomplettan P = Haemocomplettan HS (fibrinogen) | CSL Behring                 |                               |
| <input type="checkbox"/> | HEMOLEVEN (Factor XI)                               | LFB                         |                               |
| <input type="checkbox"/> | Kovaltry  | Bayer                       |                               |
| <input type="checkbox"/> | NovoSeven (=Niasstase) (activated factor VII)       | NovoNordisk                 | Price per vial:<br>Vial size: |
| <input type="checkbox"/> | Riastap   | CSL Behring                 |                               |
| <input type="checkbox"/> | Tretten rXIII                                       | NovoNordisk                 |                               |
| <input type="checkbox"/> | WILFACTIN (Von Willebrand Factor)                   | LFB                         |                               |
| <input type="checkbox"/> | Other:  |                             |                               |

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

## 24. Non-factor products used in 2017

(Please check the box on the left if a product is used, and if known, fill out the number of patients and price per dose.)

| Used                     | Brand Name            | Manufacturer | Price per Dose |
|--------------------------|-----------------------|--------------|----------------|
| <input type="checkbox"/> | Hemlibra (Emicizumab) | Roche        |                |

### Please return to:

Email: [globalsurvey@wfh.org](mailto:globalsurvey@wfh.org)

Fax: 514-875-8916

Address: **World Federation of Hemophilia**

1425 René Lévesque Boulevard West, suite 1200

Montréal, Québec, H3G 1T7

Canada

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

Comments:

## Glossary of terms

**Bernard-Soulier syndrome:** A severe congenital bleeding disorder characterized by thrombocytopenia and large platelets, due to a defect in the platelet glycoprotein 1b/V/IX receptor.

**Cryoprecipitate:** A fraction of human blood prepared from fresh plasma. Cryoprecipitate is rich in factor VIII, von Willebrand factor, and fibrinogen (factor I). It does not contain factor IX.

**Desmopressin (DDAVP):** A synthetic hormone used to treat most mild cases of von Willebrand disease and mild hemophilia A. It is administered intravenously or by subcutaneous injection or by intranasal spray.

**Factor concentrates:** These are fractionated, freeze-dried preparations of individual clotting factors or groups of factors derived from donated blood.

**Extended half-life factor concentrate:** A new generation of recombinant factor concentrates, which extend their half-life. Half-life is the time it takes for infused factor to lose half of its potency. Traditional factor VIII has a half-life of 8 to 12 hours; an extended factor VIII half-life is defined as a ratio greater than 1.3-fold, of the traditional high-life.

**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 above 5% and below 40% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%.)

**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.









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