DECEMBER 2008

World Federation of Hemophilia Report on the

ANNUAL GLOBAL SURVEY 2007

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

Report on the Annual Global Survey 2007 is published by the World Federation of Hemophilia.

All data are provisional.

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Introduction to the Report on the WFH Global Survey 2007

Report on the Annual Global Survey 2007 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. The purpose of this report is to provide useful information to hemophilia organizations, hemophilia treatment centres (HTCs), and health officials involved in efforts to reduce or prevent complications of bleeding disorders in order to assist with program planning.

Methodology

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

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization.

The 2007 survey is the ninth WFH survey. It gathers data for the years 2003, 2004, 2005, 2006 and 2007. Not all of our members are able to report every year. A list of participating countries and their data year can be found on page 17. The survey includes data on more than 214,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 105 countries.

Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed.

The survey questionnaire is included at the end of this report. The question numbers from the questionnaire (for example, B1., B2., B3.) correspond to the data in each table in the report.

Comments on the graphs

The graphs and charts found on pages 7 and 8 contain data from the history of the Global Survey. These graphs were created using aggregated numbers to demonstrate the increases in patients identified and treatment products used over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. The graphs on pages 9 to 16 use data from the 2007 and 2006 Global Surveys.

Answers were not always available for all questions. In such cases, the analysis was done using only data from countries that responded, with the number of respondents as the denominator.

Comments on data collection

Participation in the survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. This year national hemophilia organizations have supplied more complete data than last year, including information on inhibitors and the gender of patients with specific bleeding disorders.

This report provides information on the annual usage of treatment products for 2007 or 2006. It includes only those countries where the national hemophilia organization provided information. Quantities reported used were not independently verified. The amounts reported may only be factor bought through government or other sources. Not all national hemophilia organizations are able to report on all product used in their country.

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

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

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

c) The type of health care system in a country can influence data quality. A country with universal, free, state-of-the-art health care may be more likely to identify patients with hemophilia even if they don't require treatment. As well, universal health care means that all of the population accesses care through the same infrastructure making it possible to count every patient and trace families. In countries with different health care systems, it is likely that not all patients are identified.

d) Definitions may vary from country to country. Countries may use different definitions to diagnose hemophilia and other disorders. For example a US study defined hemophilia as a factor level of 30% or less, while in Canada the cut off is 50%.

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

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

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

h) Some of the differences may be due to differences in the distribution of age and perhaps race across countries. Comparisons across countries with widely disparate population distributions could result in very different prevalence estimates.

i) Immigration to wealthier countries may play a role.

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

2007 WFH Global Survey Summary

Demographics

Number of countries in this survey: **105**
Percentage of world population covered by 2007 survey: **89%**

Number of people identified with hemophilia A and B (question B1): **142,597**
Number of people identified with VWD (question B2): **52,545**
Number of people identified with other bleeding disorders (question B3): **18,762**

Total number of people with bleeding disorders identified: **213,904**

Number of people with hemophilia A (question B10): **105,018**
Number of people with hemophilia B (question B11): **21,384**

Number of countries using national registries to report these numbers: **53**

Number of hemophilia A patients with clinically identified inhibitors: **3,831**
Number of hemophilia B patients with clinically identified inhibitors: **285**

Reported number of PWH infected with HIV: **6,383**
Reported number of PWH infected with HCV: **31,707**
Reported number of patients with VWD infected with HIV: **187**
Reported number of patients with VWD infected with HCV: **1,752**

Factor usage

(76 countries reporting)

Global per capita factor VIII usage (GNP above US$10,000): **3.47 IU**
Global per capita factor IX usage (GNP above US$10,000): **0.39 IU**

Global per capita factor VIII usage (GNP between US$2,000-US$10,000): **0.31 IU**
Global per capita factor IX usage (GNP between US$2,000-US$10,000): **0.06 IU**

Global per capita factor VIII usage (GNP below US$2,000): **0.02 IU**
Global per capita factor IX usage (GNP above US$2,000): **0.001 IU**

Total reported annual global consumption of factor VIII concentrates: **5,254,945,480 IU**
Total reported annual global consumption of factor IX concentrates: **475,555,184 IU**

Figure 1: Global increase in identified patients (aggregated data, see page 4, Comments on the graphs)

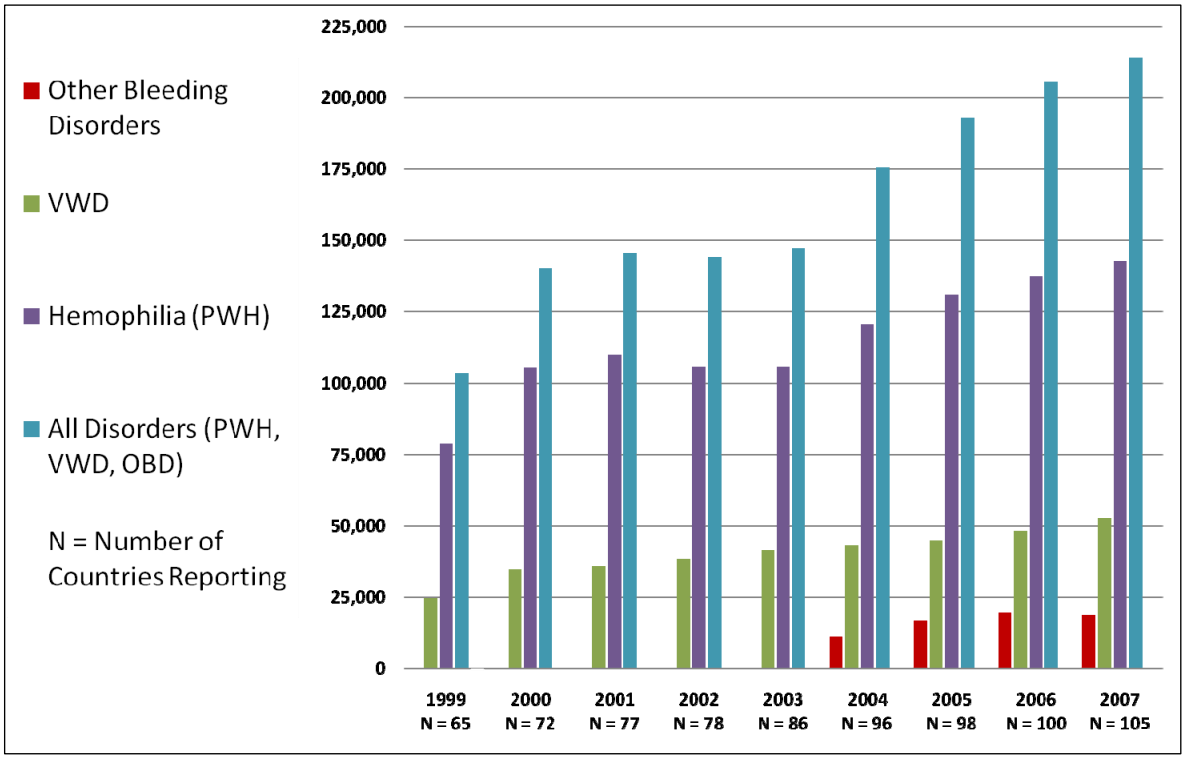


Figure 2: Von Willebrand Disease (aggregated data, see page 4, Comments on the graphs)

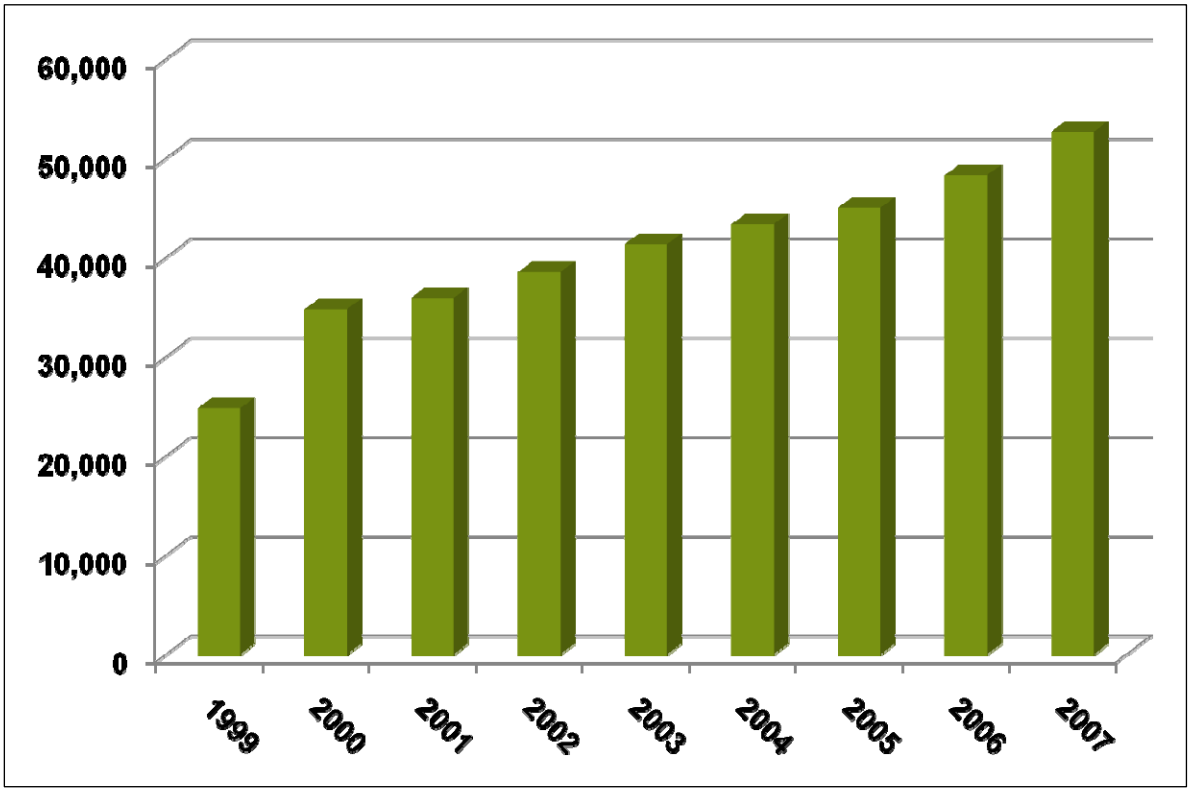


Figure 3: Other bleeding disorders (aggregated data, see page 4, Comments on the graphs)

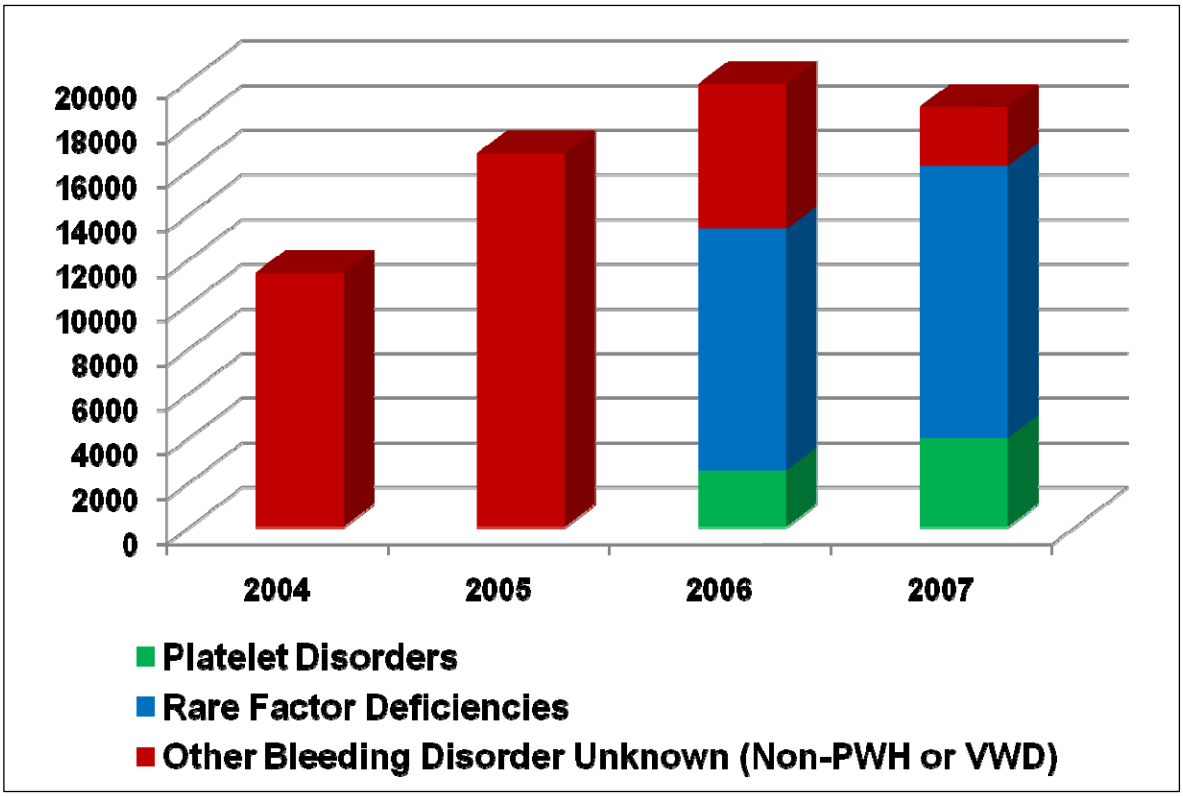
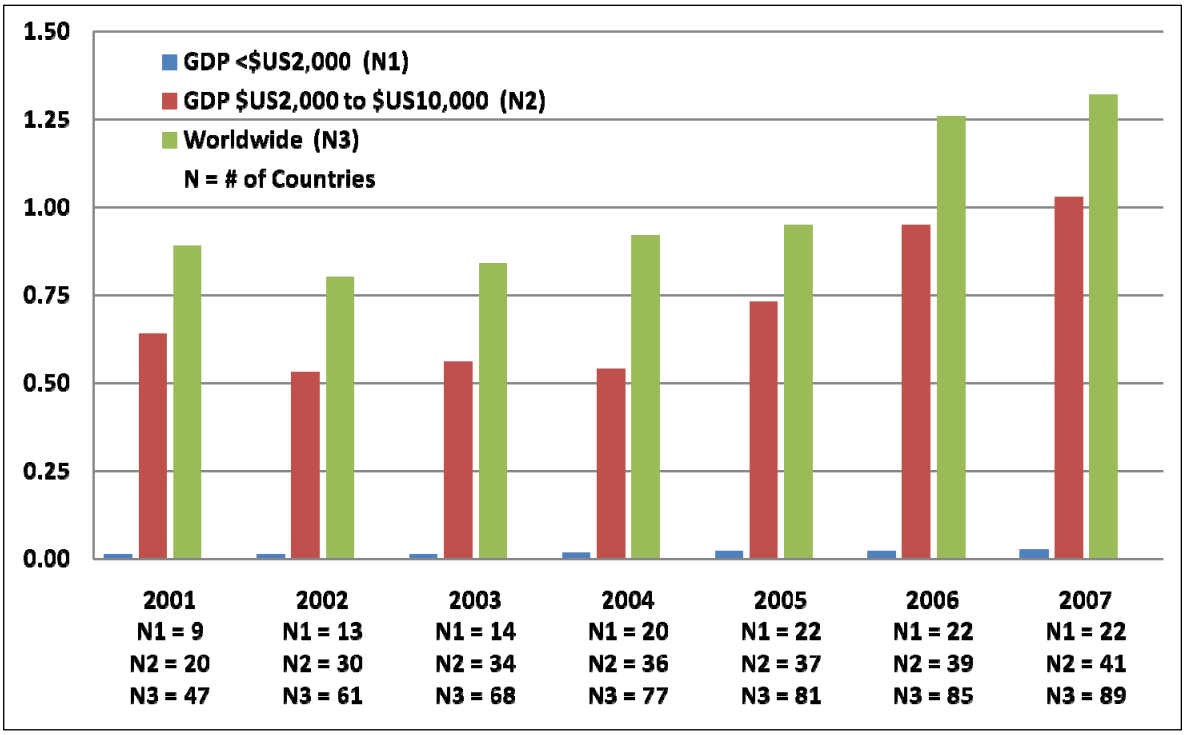


Figure 4: Per capita factor VIII use in emerging economies (aggregated data, see page 4, Comments on the graphs)



Gender distribution
The following graphs show the proportion of male and female patients for the rare bleeding disorders. (See gender data on page 25) This data is from the 60 countries that provided gender breakdowns.

Fig. 5: Gender: Von Willebrand Disease

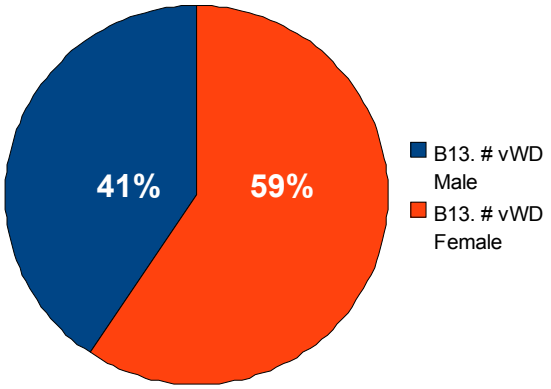


Fig. 6: Gender: Factor I Deficiency

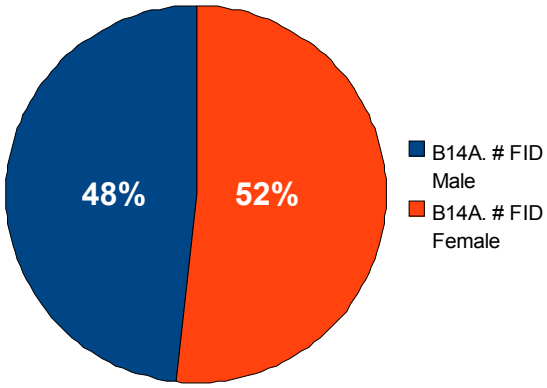


Fig. 7: Gender: Factor II Deficiency

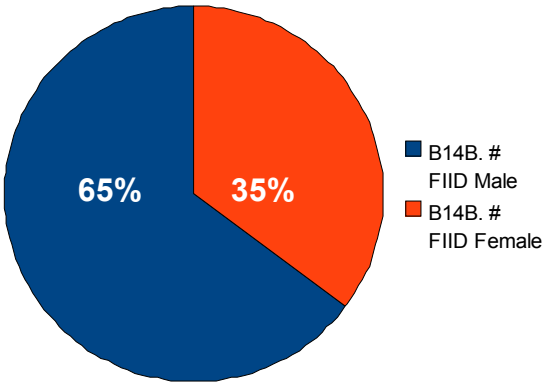


Fig. 8: Gender: Factor V Deficiency

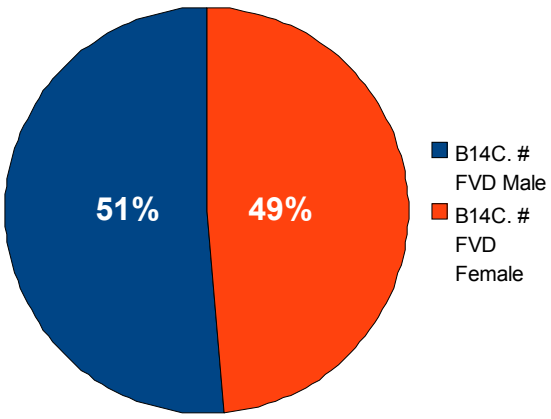


Fig. 9: Gender: Factor V+VIII Deficiency

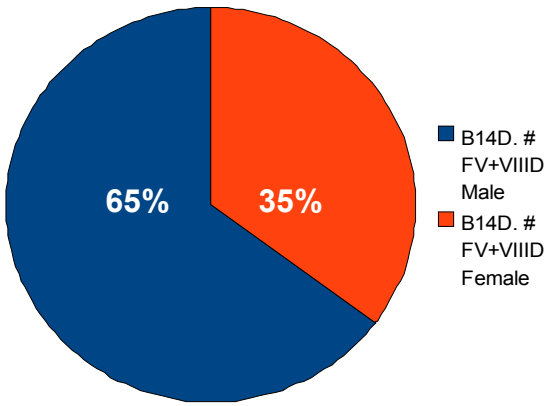


Fig. 10: Gender: Factor VII Deficiency

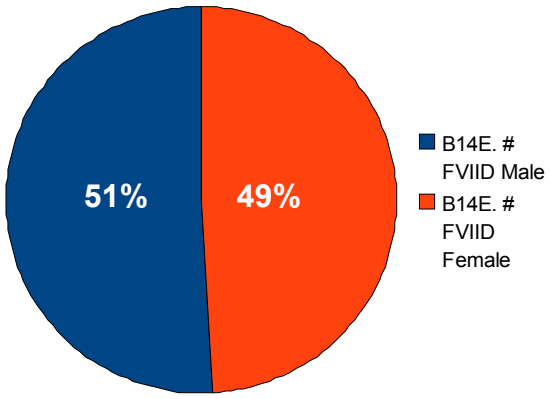


Fig. 11: Gender: Factor X Deficiency

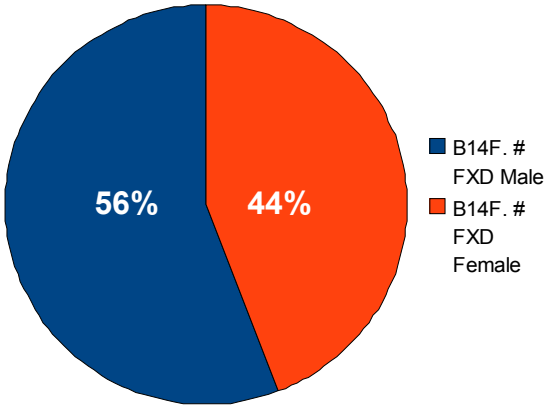


Fig. 12: Gender: Factor XI Deficiency

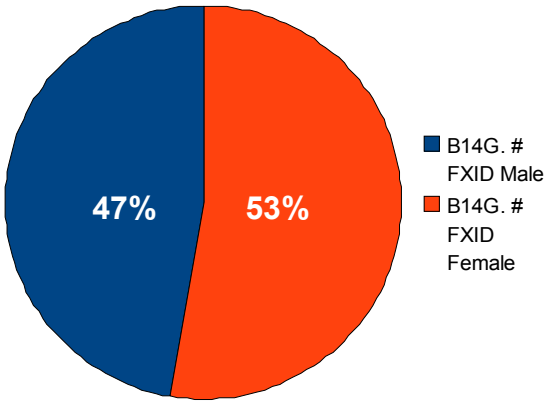


Fig. 13: Gender: Factor XIII Deficiency

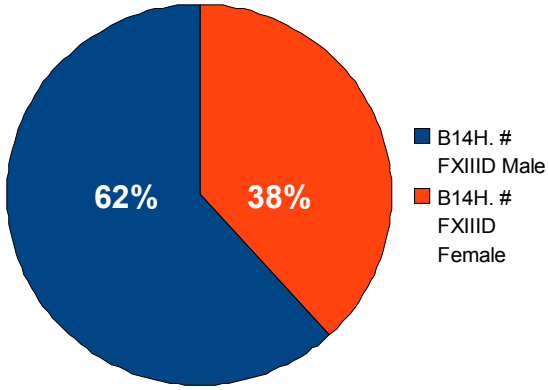


Fig. 14: Gender: Bernard Soulier Syndrome

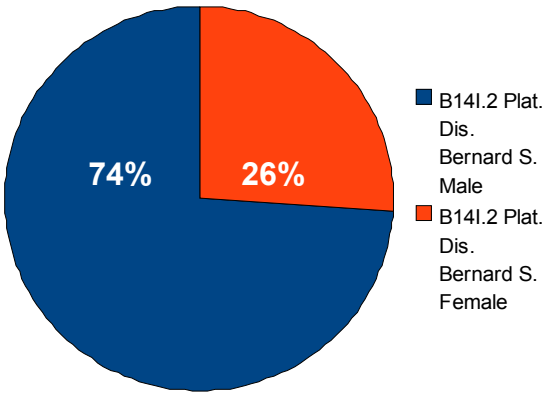


Fig. 15: Gender: Glanzmann's thrombasthenia

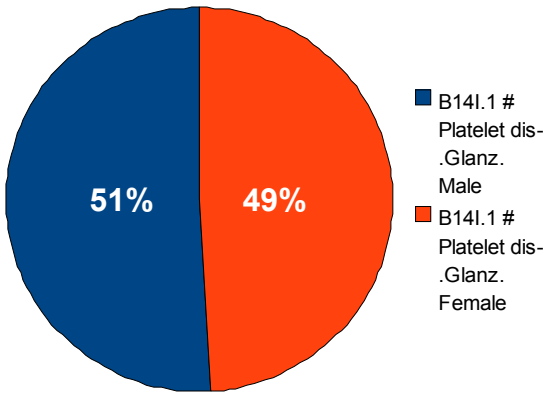
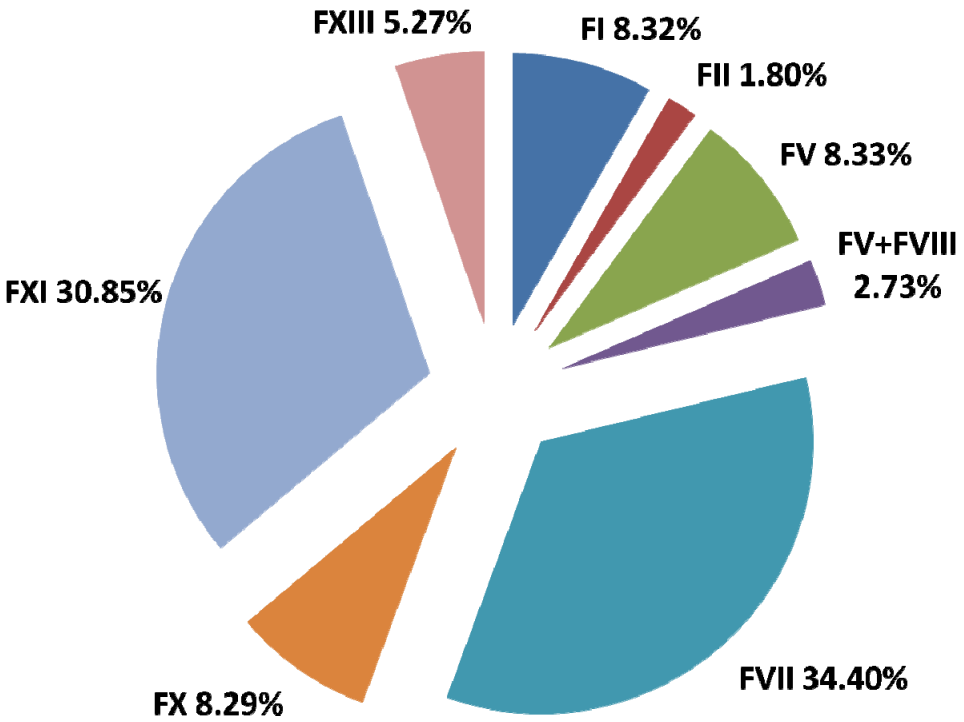


Figure 16: Distribution of identified rare factor deficiencies



Factor consumption: regional comparisons

The following charts compare the consumption of factor concentrates in various regions. Per capita figures are calculated by dividing the total number of international units (IU) reported used in a country by the total population of the country. The number of IUs is as reported to the WFH for the survey for the previous year and not independently verified. There are some countries with centralized purchasing and very accurate numbers to report. In other countries, with less centralized procurement or multiple purchasers it is difficult to get an exact figure for the yearly consumption. These data are as reported in the 2006 or 2007 Global Survey, except those countries with an asterisk (*) where the data source is data submitted to the WFH by countries participating in the Global Alliance for Progress program. These charts are intended for regional and economic comparison so countries may appear in more than one chart and these regional groupings do not follow the World Health Organization regions. The bottom two bars on each chart show the global average, that is, all countries that fall into that economic category. Please note that the scale along the bottom of each chart (the x-axis) changes from region to region.

Figure 17: Africa IU per capita

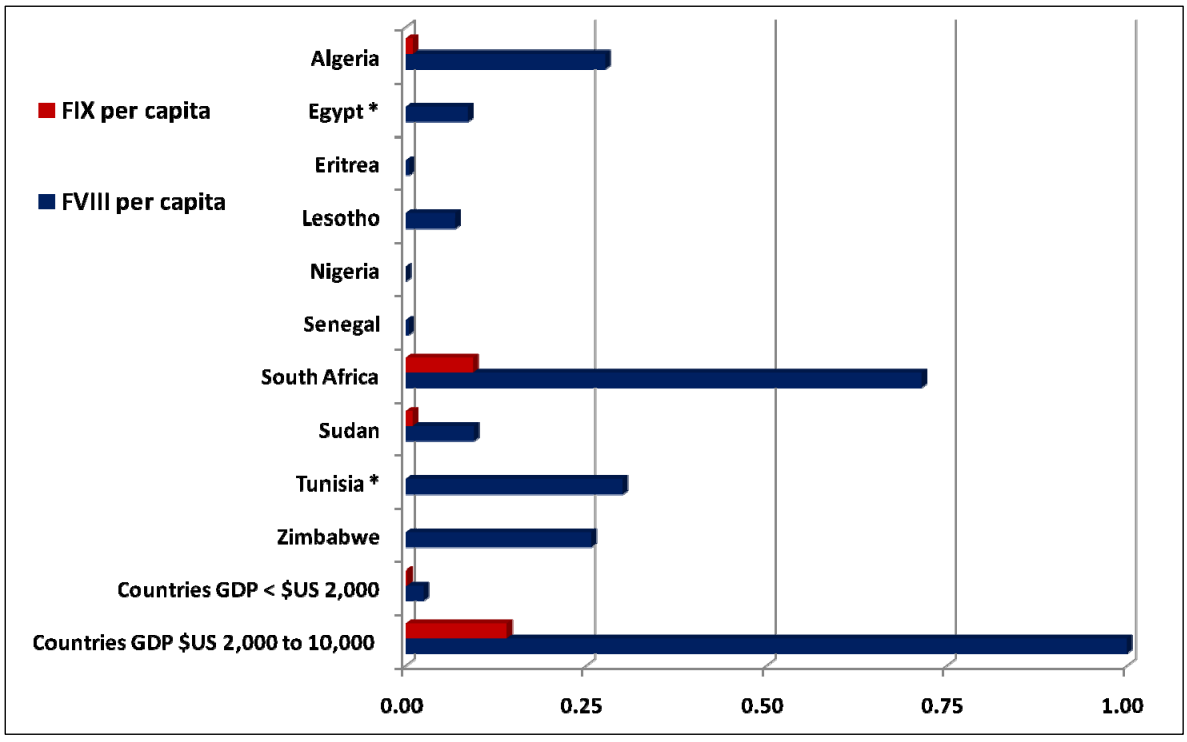


Figure 18: East Mediterranean IU per capita

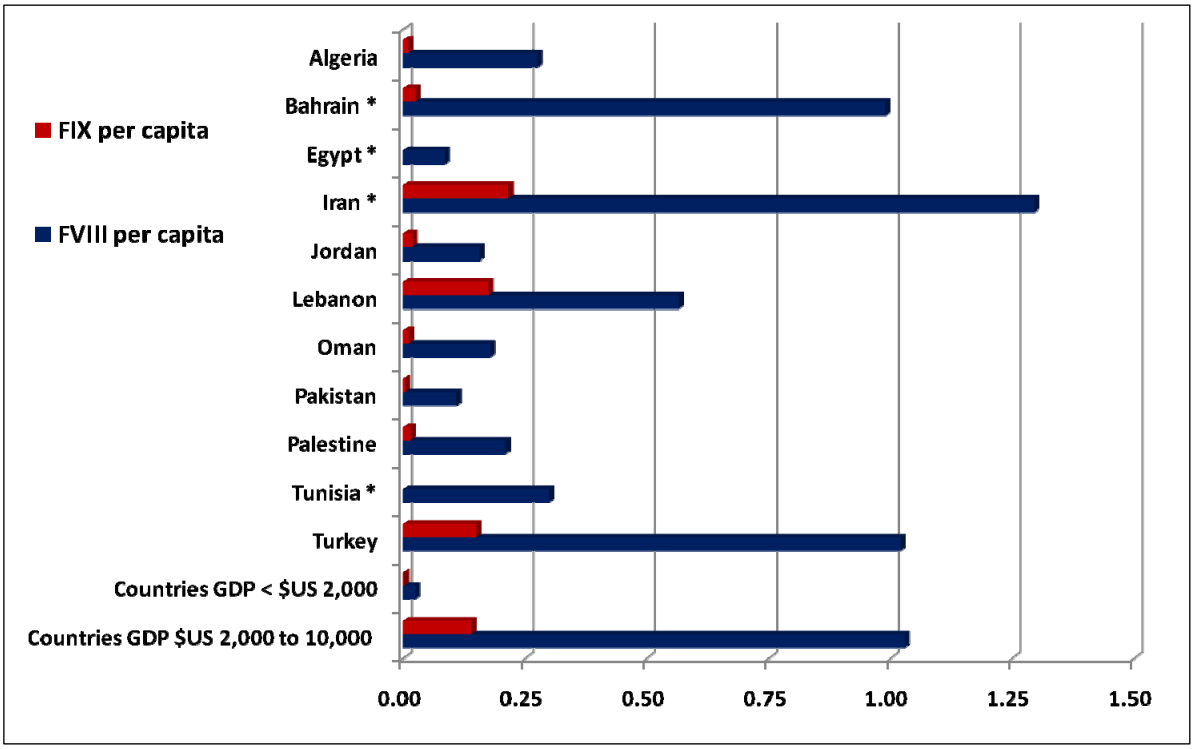


Figure 19: Central Europe IU per capita

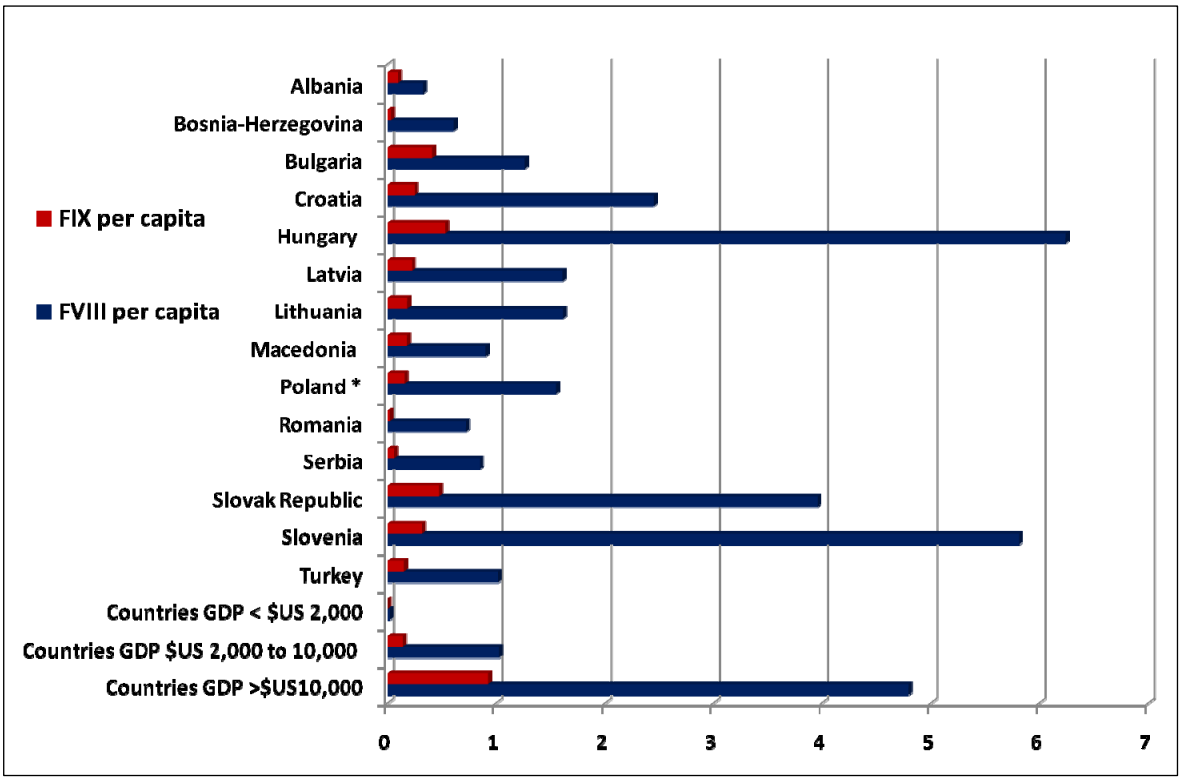


Figure 20: Eastern Europe IU per capita

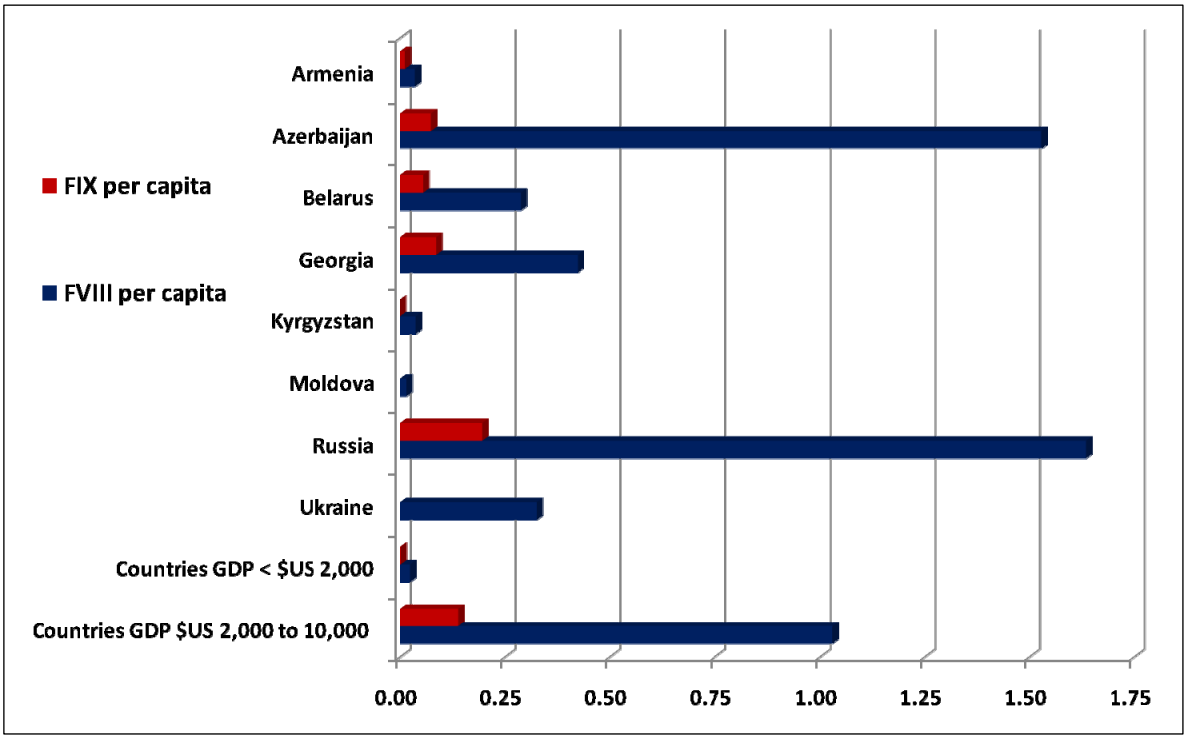


Figure 21: Western Europe IU per capita

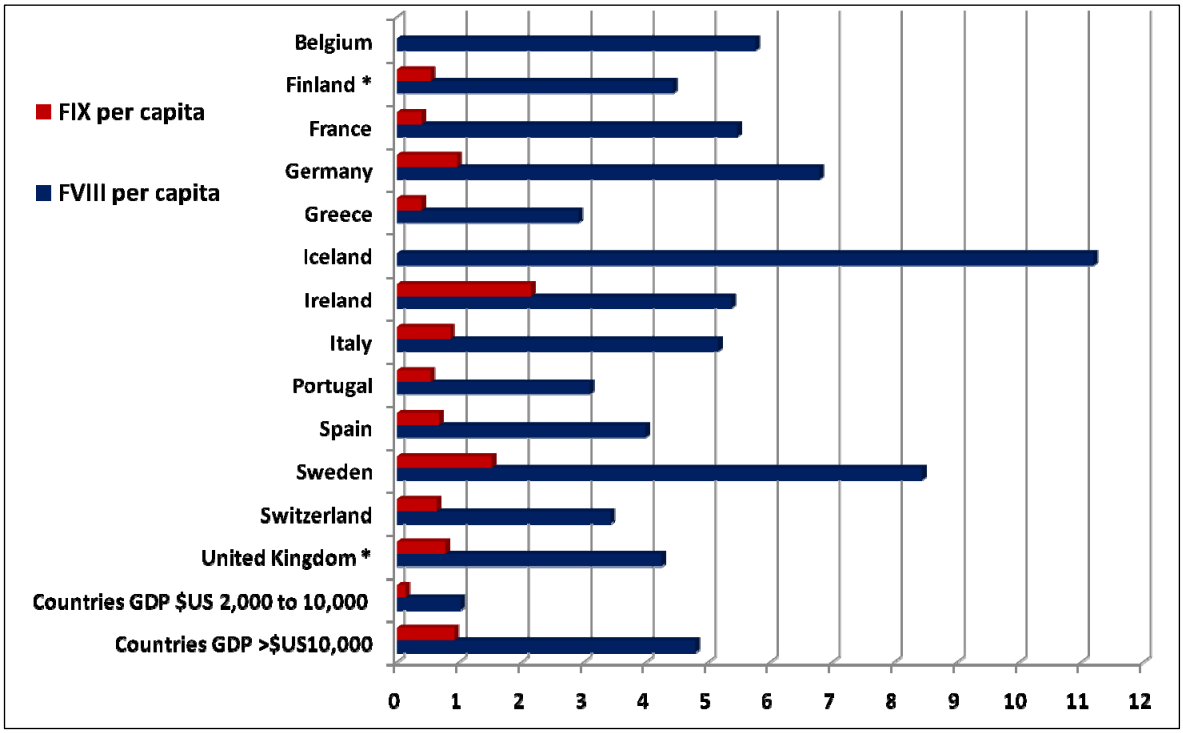


Figure 22: Asia South-East IU per capita

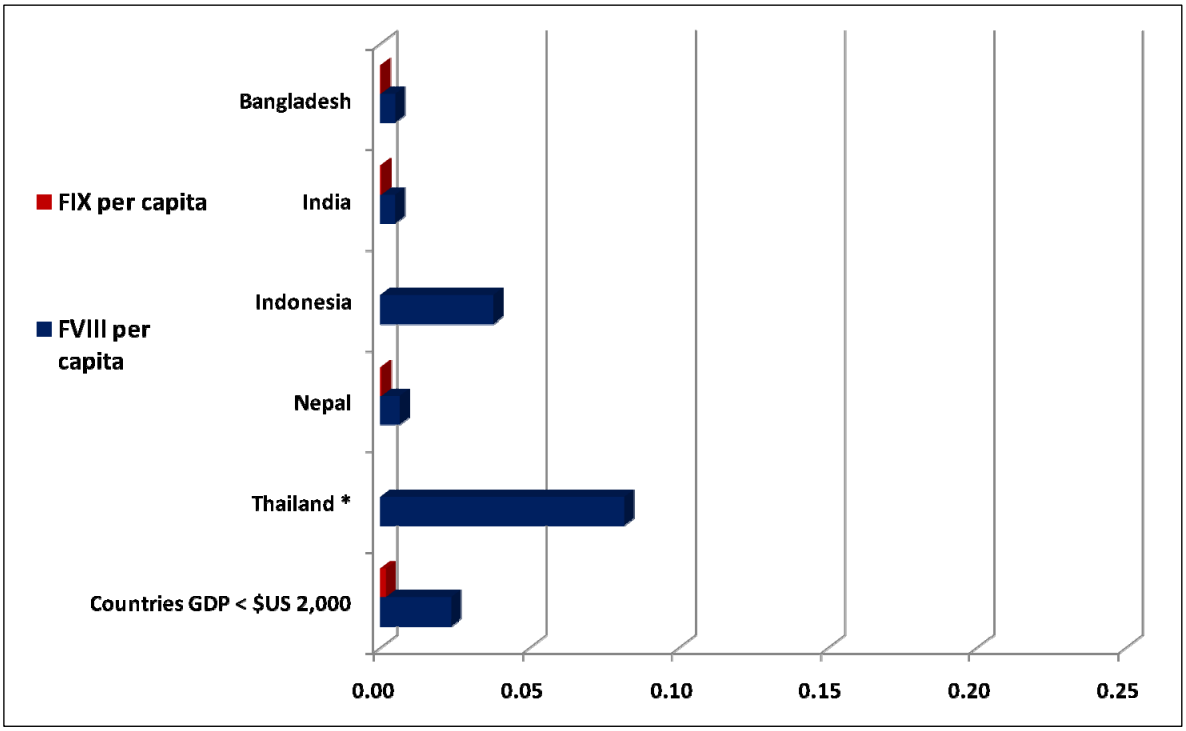


Figure 23: Western Pacific IU per capita

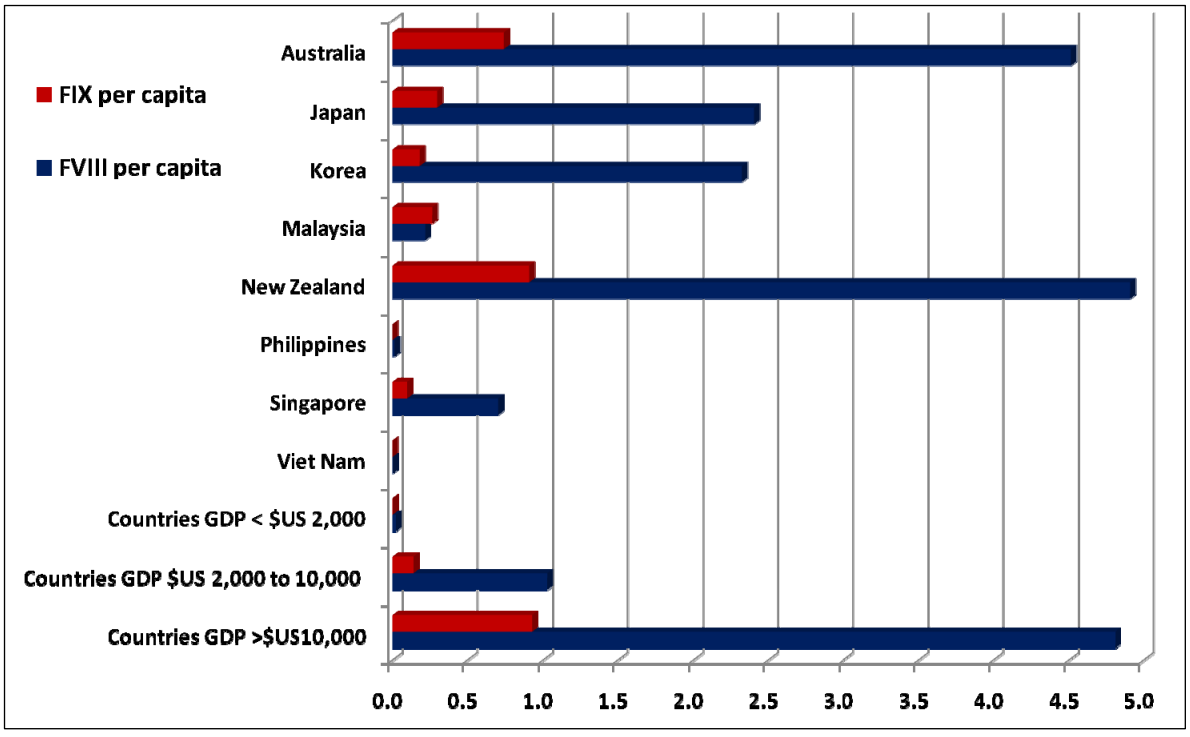


Figure 24: Latin America IU per capita

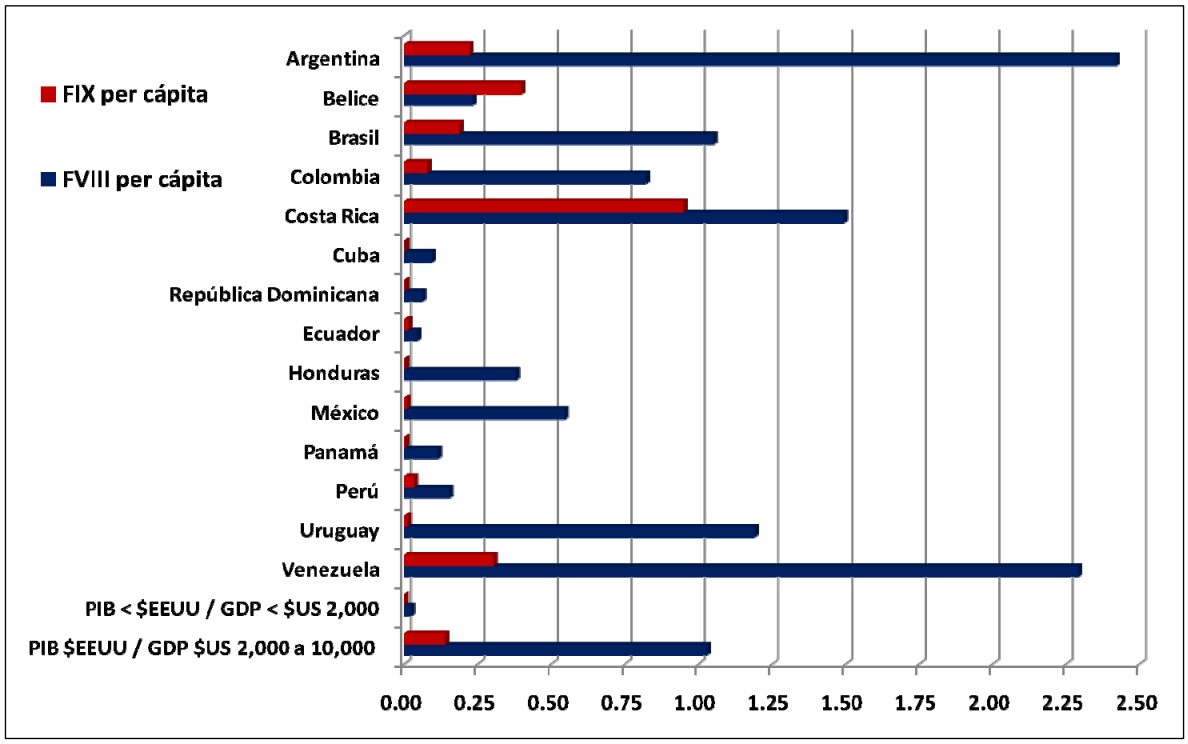
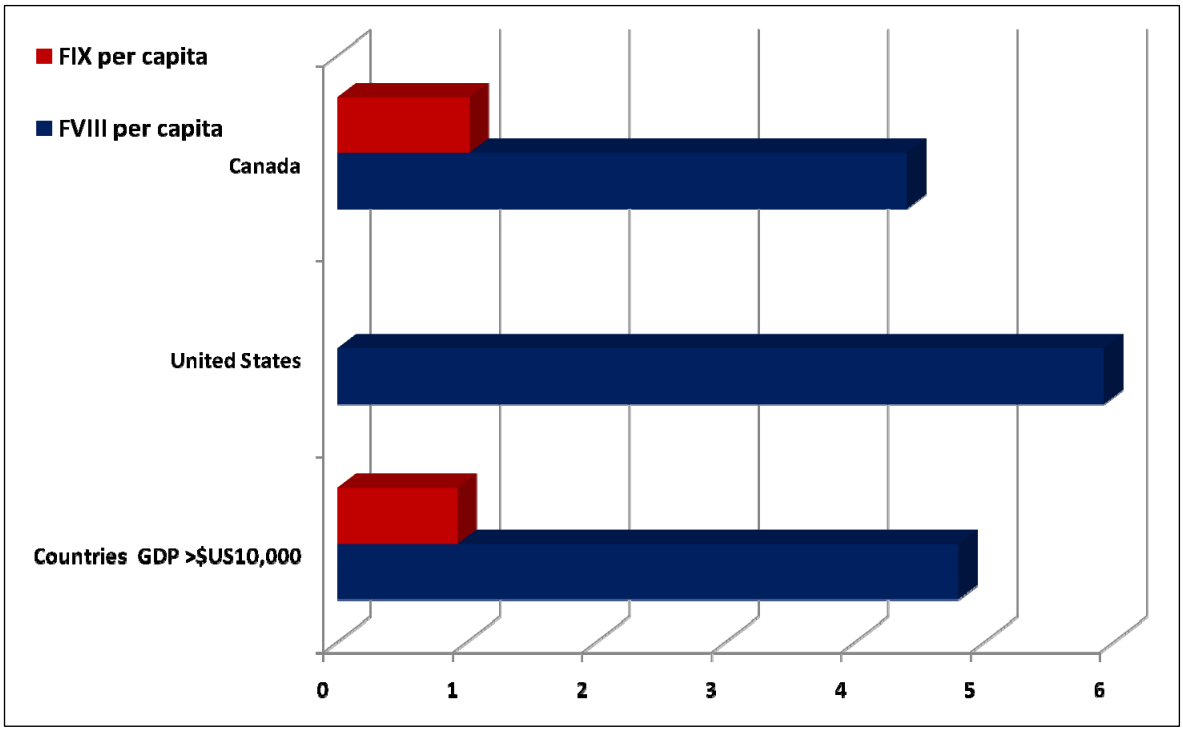


Figure 25: North America IU per capita



Countries included in the 2007 WFH Global Survey

The year beside each country indicates the year of the data used in this report. For this report, 79 countries reported data for 2007, the data for the other countries is from their most recent report.

1. Albania 2007
2. Algeria 2007
3. Argentina 2007
4. Armenia 2007
5. Australia 2007
6. Austria 2007
7. Azerbaijan 2007
8. Bahrain 2007
9. Bangladesh 2007
10. Belarus 2006
11. Belgium 2006
12. Belize 2004
13. Bosnia-Herzegovina 2006
14. Brazil 2007
15. Bulgaria 2006
16. Cambodia 2007
17. Cameroon 2007
18. Canada 2007
19. Chile 2003
20. China 2007
21. Colombia 2007
22. Costa Rica 2007
23. Croatia 2007
24. Cuba 2007
25. Cyprus 2004
26. Denmark 2005
27. Dominican Republic 2007
28. Ecuador 2007
29. Egypt 2007
30. El Salvador 2004
31. Eritrea 2007
32. Estonia 2003
33. Finland 2007
34. France 2007
35. Georgia 2007
36. Germany 2007
37. Greece 2007
38. Guatemala 2005
39. Honduras 2007
40. Hungary 2007
41. Iceland 2007
42. India 2007
43. Indonesia 2007
44. Iran 2007
45. Iraq 2007
46. Ireland 2007
47. Israel 2007
48. Italy 2007
49. Jamaica 2004
50. Japan 2007
51. Jordan 2006
52. Kenya 2007
53. Korea 2007
54. Kuwait 2005
55. Kyrgyzstan 2007
56. Latvia 2007
57. Lebanon 2004
58. Lesotho 2007
59. Lithuania 2007
60. Macedonia 2006
61. Malaysia 2007
62. Malta 2003
63. Mexico 2007
64. Moldova 2007
65. Mongolia 2007
66. Nepal 2007
67. Netherlands 2007
68. New Zealand 2007
69. Nicaragua 2006
70. Nigeria 2005
71. Norway 2006
72. Oman 2007
73. Pakistan 2007
74. Palestine 2007
75. Panama 2007
76. Peru 2007
77. Philippines 2007
78. Poland 2007
79. Portugal 2007
80. Qatar 2006
81. Romania 2007
82. Russia 2007
83. Saudi Arabia 2007
84. Senegal 2007
85. Serbia 2007
86. Singapore 2006
87. Slovak Republic 2007
88. Slovenia 2007
89. South Africa 2007
90. Spain 2006
91. Sri Lanka 2007
92. Sudan 2007
93. Sweden 2007
94. Switzerland 2007
95. Thailand 2007
96. Tunisia 2006
97. Turkey 2007
98. Ukraine 2007
99. United Kingdom 2007
100. United States 2007
101. Uruguay 2007
102. Uzbekistan 2006
103. Venezuela 2007
104. Viet Nam 2007
105. Zimbabwe 2006

Population Statistics

A **registry** is a regularly updated centralized list of identified people with hemophilia or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment and complications**.** An **HTC** is a Hemophilia Treatment Centre. **OBD** stands for Other Bleeding Disorders (ie. not hemophilia or von Willebrand Disease.)

Country	B1. # of people with hemophilia	B2. # people with VWD	B3. # people with OBD	B4a.Source of data
Albania	265			Registry
Algeria	1,291	109		HTCs
Argentina	1,952	347		Registry
Armenia	210	7	3	Registry
Australia	1,760	1,308	629	Registry
Austria	500			HTCs
Azerbaijan	846	218	40	Registry
Bahrain	20		4	HTCs
Bangladesh	351		6	Registry
Belarus	559			Other
Belgium	831	850	115	Other
Belize	14			Registry
Bosnia-Herzegovina	140	30		
Brazil	8,172	2,333	316	HTCs
Bulgaria	572	69	27	Registry
Cambodia	42	1		Registry
Cameroon	63			HTCs
Canada	3,030	2,818	997	Registry
Chile	1,027			Registry
China	5,126	227		
Colombia	1,564	134	143	Registry
Costa Rica	173			Registry
Croatia	477	282	139	Registry
Cuba	370	29	93	Registry
Cyprus	103			Other
Denmark	445	334	109	HTCs
Dominican Republic	334	65	15	Registry
Ecuador	393	50	13	Registry
Egypt	4,323	414	854	Registry
El Salvador	254			Other
Eritrea	36			Other

Country	B1. # of people with hemophilia	B2. # people with VWD	B3. # people with OBD	B4a.Source of data
Estonia	39			
Finland	317	2,808	36	Other
France	4,389	609	215	Registry
Georgia	238	5	18	Registry
Germany	4,790	3,100		HTCs
Greece	872	679	227	HTCs
Guatemala	123	14	72	HTCs
Honduras	198	5	4	Registry
Hungary	1,027	1,361	400	Registry
Iceland	64	96		HTCs
India	13,448			HTCs
Indonesia	1,167	27		Registry
Iran	4,864	777	1,343	
Iraq	736	143	136	HTCs
Ireland	625	820	423	Registry
Israel	489			HTCs
Italy	3,270	1,650	700	HTCs
Jamaica	108			Registry
Japan	5,000	843	406	HTCs
Jordan	248		45	Registry
Kenya	461	22		Other
Korea	1,765	92	68	Registry
Kyrgyzstan	206			Other
Latvia	124	68	2	HTCs
Lebanon	110			Other
Lesotho	23	1		HTCs
Lithuania	147	134	42	HTCs
Macedonia	280	40		HTCs
Malaysia	1,065	386	366	Registry
Mexico	3,821	104	0	Other
Moldova	222	2		HTCs
Mongolia	49	2	4	HTCs
Nepal	242		3	HTCs
Netherlands	1,483	258	64	Registry
New Zealand	362	134	19	Other
Nicaragua	227	37	5	HTCs
Nigeria	42	3	4	Other

Country	B1. # of people with hemophilia	B2. # people with VWD	B3. # people with OBD	B4a.Source of data
Norway	379	823	41	Registry
Oman	85	253	272	Registry
Pakistan	1,700	45	11	Registry
Palestine	127	5	50	Registry
Panama	231	323	16	Registry
Peru	456	38	16	HTCs
Philippines	923	26		Registry
Poland	2,466	1,001	314	Registry
Portugal	518	49	142	Other
Qatar	112	7	62	Registry
Romania	1,510	320	56	Registry
Russia	5,418	1,196	569	HTCs
Saudi Arabia	183			Registry
Senegal	111	5	3	HTCs
Serbia	456	217	15	Registry
Singapore	204	58	85	Registry
Slovak Republic	535	411	657	Registry
Slovenia	192	115	73	Registry
South Africa	1,715	511	210	Registry
Spain	1,920	683	289	Registry
Sri Lanka	252	2		Other
Sudan	459	54	64	HTCs
Sweden	798	1,459		HTCs
Switzerland	640	110	23	Registry
Thailand	800			Registry
Tunisia	270	65		HTCs
Turkey	3,057	283	399	Registry
Ukraine	2,600			HTCs
United Kingdom	6,061	7,852	4,999	HTCs
United States	15,904	11,974	1,612	HTCs
Uruguay	152			Registry
Uzbekistan	1,138	86	33	Registry
Venezuela	1,808	698	504	Registry
Viet Nam	1,231	30	142	Registry
Zimbabwe	302	1		Registry
TOTALS	**142,597**	**52,545**	**18,762**	

Demographic Details

B10. Hemophilia A
B11. Hemophilia B
B12. Hemophilia, type unknown
B13. von Willebrand disease
B14a. Other hereditary bleeding disorders: Factor I deficiency
B14b. Other hereditary bleeding disorders: Factor II deficiency
B14c. Other hereditary bleeding disorders: Factor V deficiency
B14d. Other hereditary bleeding disorders: Factor V+VIII deficiency
B14e. Other hereditary bleeding disorders: Factor VII deficiency
B14f. Other hereditary bleeding disorders: Factor X deficiency
B14g. Other hereditary bleeding disorders: Factor XI deficiency
B14h. Other hereditary bleeding disorders: Factor XIII deficiency
B14i.1 Platelet disorders: Glanzmann's thrombasthenia
B14i.2 Platelet disorders: Bernard Soulier Syndrome
B14i.3 Platelet disorders: other or unknown
B14j. Other hereditary bleeding disorders: type unknown

Country	**B10**. Hemophilia A	**B11.** Hemophilia B	**B12.** Hemophilia type unknown	**B13.** von Willebrand disease	**B14a.** Factor I deficiency	**B14b.** Factor II deficiency	**B14c.** Factor V deficiency	**B14d.** Factor V + VIII deficiency	**B14e.** Factor VII deficiency	**B14f.** Factor X deficiency	**B14g.** Factor XI deficiency	**B14h.** Factor XIII deficiency	**B14i.1** Glanzmann's thrombasthenia	**B14i.2** Bernard Soulier Syndrome	**B14i3** Platelet disorders: other	**B14j**. Oth. hereditary bleeding disorders
Albania	238	27							2							
Algeria	962	200	120													
Argentina	1,714	238		347												
Armenia	189	6	4	8	3					4						
Australia	1,410	350		1,308			7		36	6	92	14			91	10
Azerbaijan	810	36	32	218		3			3	1				1	4	6
Bahrain	19	1							1	3			2	1		
Bangladesh	306	45	5									1				
Belarus	463	96														
Bosnia-Herzegovina	100	10		30												
Brazil	6,881	1,291		2,333	11	1	35	12	101	20	39	16	57	1		219
Bulgaria	507	65	2	69	10	1			10	3	1					
Cambodia	38	4		1												
Cameroon	60	3														
Canada	2,435	595	0	2,818	75	6	32	5	182	27	256	42	37	23	312	

Country	**B10**. Hemophilia A	**B11**. Hemophilia B	**B12**. Hemophilia type unknown	**B13**. von Willebrand disease	**B14a**. Factor I deficiency	**B14b**. Factor II deficiency	**B14c**. Factor V deficiency	**B14d**. Factor V + VIII deficiency	**B14e**. Factor VII deficiency	**B14f**. Factor X deficiency	**B14g**. Factor XI deficiency	**B14h**. Factor XIII deficiency	**B14i.1** Glanzmann's thrombasthenia	**B14i.2** Bernard Soulier Syndrome	**B14i3** Platelet disorders: other	**B14j**. Oth. hereditary bleeding disorders
Colombia	1,192	259	113	134	17	9	8	2	15	1	8	6	6	2	20	49
Costa Rica	145	28									1					
Croatia	385	92	0	282	6	0	12	3	48	3	19	7			17	3
Cuba	309	61	0	29	2	1	1	0	0	0	4	1	1	0	83	0
Denmark	352	93	0	334	0	1	2	0	35	7	6	9	22			
Dominican Republic	194	21	61	65			0	1	1	12			2			
Ecuador	354	39		50	1	0	1	0	2	1	3	1				2
Egypt	3,365	848		414	106	1	140	9	68	75	87	17	31	2		
Eritrea	31	5														
Finland	247	70	0	2,808	4	1	5	0	7	4	2	13	0	20		
France	3,618	771	0	609	27	0	22	4	66	12	66	18				0
Georgia	198	40	0	15	0	0	0	0	1	0	0	1	4	0	0	5
Germany	4,055	745	1,200	3,100												
Greece	739	133		679	16		7		47	6	48	10	12	11	70	3
Guatemala	114	9		14												
Honduras	182	16	23	5					1		1	2				
Hungary	829	198		1,361	14	6	19		173	18	63	3	7	2	52	
Iceland	63	2	0	96									0	12		
India	10,982	1,939	527													
Indonesia	233	33														
Iran	4,014			777	67	14	72	126	226	104	50	89	212	24	359	
Iraq	553	183		143	26		1		36	6	1	6			65	
Ireland	446	198	0	820	0	0	45	0	42	62	81	3	9	3	125	67
Israel	407	82														
Italy	2,697	573	21	1,650	49	14	73	23	308	54	156	21			115	45
Japan	4,100	900		843	57	5	22	6	43	14	20	53				
Jordan	202	46					1		51	3	3	6				
Korea	1,457	308	12	92	4		2	8	17		11	3				6
Kyrgyzstan	197	9											1			

Country	**B10**. Hemophilia A	**B11.** Hemophilia B	**B12.** Hemophilia type unknown	**B13.** von Willebrand disease	**B14a.** Factor I deficiency	**B14b.** Factor II deficiency	**B14c.** Factor V deficiency	**B14d.** Factor V + VIII deficiency	**B14e.** Factor VII deficiency	**B14f.** Factor X deficiency	**B14g.** Factor XI deficiency	**B14h.** Factor XIII deficiency	**B14i.1** Glanzmann's thrombasthenia	**B14i.2** Bernard Soulier Syndrome	**B14i3** Platelet disorders: other	**B14j**. Oth. hereditary bleeding disorders
Latvia	104	20		68					2							
Lesotho	23	0		1												
Lithuania	126	21		134			2		25	1	1	2			11	
Macedonia	200	80		40												
Malaysia	902	163	0	386	4	2	13		52	13	43	11	36		76	
Mexico	3,023	472	326	104					2	1						
Moldova	143	14	65	2												
Mongolia	49	4		2												
Nepal	211	30							1	3						
Netherlands	1,238	245		258	1	3	3		12	1	3	16	25			
New Zealand	297	65		134												19
Nicaragua	205	22		37	4											
Nigeria	32	5	5	3												
Norway	283	96		823	3	0	4		25							
Oman	80	5		253	5	1	3	5	47	3	13	1	22	2	132	
Pakistan	1,050	650		45	3	8										
Palestine	102	25		5	10	0	2	0	0	5	0	0	34	1		
Panama	206	25		323					4	12			1	1		
Peru	283	45	128	38			3		4	2	4		2	1		
Philippines	797	126	43	26												
Poland	2,104	362		1,001	35	0	15	3	160	15	24	9	15	5	14	26
Portugal	507	100	40	49	2		3				7	1				
Qatar	87	25		7	2		6	1	6	2	20	1				
Romania	1,339	171		320	2			2	7	2	1		1		41	
Russia	4,381	676	361	1,196												
Senegal	106	5		5												
Serbia	392	64		217	1			1	4		4	4				1
Singapore	176	28	0	58	0	0	15	0	9	0	46	3				
Slovak Republic	365	70	0	411	49	0	39	2	497	10	27	3	10	6	14	0

Country	**B10**. Hemophilia A	**B11.** Hemophilia B	**B12.** Hemophilia type unknown	**B13.** von Willebrand disease	**B14a.** Factor I deficiency	**B14b.** Factor II deficiency	**B14c.** Factor V deficiency	**B14d.** Factor V + VIII deficiency	**B14e.** Factor VII deficiency	**B14f.** Factor X deficiency	**B14g.** Factor XI deficiency	**B14h.** Factor XIII deficiency	**B14i.1** Glanzmann's thrombasthenia	**B14i.2** Bernard Soulier Syndrome	**B14i3** Platelet disorders: other	**B14j**. Oth. hereditary bleeding disorders
Slovenia	173	19		115			8		9	1	11		2		7	
South Africa	1,448	266		511	9	0	42	4	18	10	28	6	15	23	47	
Spain	1,645	275		683	15	3	14	3	22	8	24	20	6	16		
Sri Lanka	184	36	32	2												
Sudan				54		0					0					
Sweden	620	178		1,459		2	1		159	13	43	5	9	7		
Switzerland	531	109		109	9			4	22	3	3	14				
Thailand	263	46		59					13	1				27		
Tunisia	219	51		62	26			3	25	5		12	138	4		
Turkey	2,504	534	8	283		3	6	23	103	47	9	4	16	3	37	167
United Kingdom	4,991	1,070		7,852	156	6	112	22	517	170	1,566	49	91	50	973	
United States	12,147	3,757		11,974	89	49	148		615	94	520	97				
Uruguay	133	19														
Uzbekistan	798	110		77		7			3				33	5	1	
Venezuela	1,424	384		698	40	59	15	29	87	83	149	9	20	6	33	3
Viet Nam	1,033	198	1	30	2	2	2	15	4	7	1	0	47	0	89	14
Zimbabwe	302	50		1												
Total	**105,018**	**21,384**	**3,129**	**51,367**	**962**	**208**	**963**	**316**	**3,976**	**958**	**3,565**	**609**	**926**	**259**	**2788**	**645**

Gender breakdowns (60 countries reporting)

Disorder			Disorder	
B10. # hemophilia A Total	64452		B14J. # Bleeding Dis.: Type Unknown Total	288
B10. # hemophilia A Male	63120		B14J. # Bleeding Dis.: Type Unknown Male	134
B10. # hemophilia A Female	1332		B14J. # Bleeding Dis.: Type Unknown Female	154
B11. # hemophilia B Total	14607		B14I.1 # Platelet dis.Glanz. Total	457
B11. # hemophilia B Male	14113		B14I.1 # Platelet dis.Glanz. Male	233
B11. # hemophilia B Female	494		B14I.1 # Platelet dis.Glanz. Female	224
B12. # hemophilia type unknown Total	631		B14I.2 Plat. Dis. Bernard S. Total	350
B12. # hemophilia type unknown Male	612		B14I.2 Plat. Dis. Bernard S. Male	259
B12. # hemophilia type unknown Female	19		B14I.2 Plat. Dis. Bernard S. Female	91
B13. # VWD Total	36581		B14I.3 Plat. Dis. Other/Un. Total	2788
B13. # VWD Male	14849		B14I.3 Plat. Dis. Other/Un. Male	949
B13. # VWD Female	21732		B14I.3 Plat. Dis. Other/Un. Female	1264
B14A. # FID Total	685			
B14A. # FID Male	331			
B14A. # FID Female	354			
B14B. # FIID Total	162			
B14B. # FIID Male	105			
B14B. # FIID Female	57			
B14C. # FVD Total	627			
B14C. # FVD Male	322			
B14C. # FVD Female	305			
B14D. # FV+VIIID Total	230			
B14D. # FV+VIIID Male	149			
B14D. # FV+VIIID Female	81			
B14E. # FVIID Total	2850			
B14E. # FVIID Male	1451			
B14E. # FVIID Female	1399			
B14F. # FXD Total	714			
B14F. # FXD Male	399			
B14F. # FXD Female	315			
B14G. # FXID Total	3036			
B14G. # FXID Male	1437			
B14G. # FXID Female	1599			
B14H. # FXIIID Total	455			
B14H. # FXIIID Male	281			
B14H. # FXIIID Female	174			

Patients with clinically identified inhibitors

Country	B10. Hemophila A Total patients	B15b. Hemophila A Patients with clinically identified inhibitors	B11. Hemophila B Total patients	B16b. Hemophila B Patients with clinically identified inhibitors
Argentina	1,714	51	238	2
Armenia	189	2		
Australia	1,410	58	350	4
Azerbaijan	810	4		
Belarus	463	29		
Brazil	6,881	293	1,291	10
Bulgaria	507	29		
Cambodia	38	0	4	0
Canada	2,435	83	595	4
Colombia	1,192	228	259	30
Costa Rica	145	19	28	0
Cuba	309	40	61	2
Egypt	3,365	14		
Finland	247	25	70	1
France	3,618	54	771	2
Georgia	198	1	40	0
Germany	4,055	94	745	14
Greece	739	14	133	2
Honduras	182	1		
Hungary	829	18	198	1
Iceland	63	0	2	0
Indonesia	233	43		
Iran	4,014	160		5
Iraq	553	6		
Ireland	446	7	198	1
Italy	2,697	288	573	8
Japan	4,100	215	900	35
Jordan	202	18	46	0
Korea	1,457	61	308	9
Latvia	104	2	20	1
Lesotho	23	2	0	0
Lithuania	126	6		
Macedonia	200	3	80	1
Malaysia	902	65	163	2

Country	B10. Hemophila A Total patients	B15b. Hemophila A Patients with clinically identified inhibitors	B11. Hemophila B Total patients	B16b. Hemophila B Patients with clinically identified inhibitors
Mexico	3,023	87	472	2
New Zealand	297	23		
Nicaragua	205	5		
Norway	283	0	96	9
Oman	80	6	5	0
Palestine	102	9	25	0
Panama	206	12	25	0
Philippines	797	11	126	0
Poland	2,104	152	362	3
Saudia Arabia		54		5
Serbia	392	15	64	0
Singapore	176	10	28	0
Slovak Republic	365	13	70	1
Slovenia	173	4		
South Africa	1,448	139	266	5
Spain	1,645	57	275	5
Sudan		2		0
Sweden	620	24	178	4
Switzerland	531	19	109	1
Thailand	263	37	46	1
Tunisia	219	6	51	0
Turkey	2,504	210	534	35
United Kingdom	4,991	100	1,070	5
United States	12,147	799	3,757	73
Uzbekistan	798	34		
Venezuela	1,424	58	384	2
Viet Nam	1,033	10	198	0
Zimbabwe	302	2		
TOTAL:	**80,574**	**3,831**	**15,214**	**285**

HIV and HCV infection

Country	B1. Total people with hemophilia	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Total people with VWD	B28. VWD HIV infection	B29. VWD HCV infection
Albania	265	1	233			
Argentina	1,952	71	637	347	0	10
Armenia	210	1	164	7		5
Australia	1,760	103	643	1,308	4	70
Austria					30	
Azerbaijan	846	0	592	218		152
Bangladesh	351		1			
Brazil	8,172	357	1,942	2,333	14	168
Bulgaria	572	9	516	69	0	50
Canada	3,030	222	830	2,818	6	66
Colombia	1,564	15	85	134	0	3
Costa Rica	173	17	58			
Croatia	477	6	198	282	0	25
Cuba	370	4	126	29	0	5
Denmark	445	30	87	334	0	1
Dominican Republic				65	1	0
Finland	317	2	137			
France	4,389	439	1,599	609	12	107
Georgia	238	0	99	5	0	1
Germany	4,790	436	3,000			
Greece	872	66	328	679	1	33
Guatemala	123	0	26	14	0	0
Honduras	198		1			
Hungary	1,027	19		1,361		93
Iceland	64	0	9	96	0	0
India	13,448	142				
Indonesia	1,167	0	63			
Iran	4,864	50	2,500	777	1	50
Iraq	736		185	143		25
Ireland	625	39	217	820		8
Israel	489	25	172			
Italy	3,270	220	1,156	1,650	7	69
Japan	5,000	816	2,485	843	7	120
Korea	1,765	20	653	92	0	5
Kyrgysztan	206		165			

Country	B1. Total people with hemophilia	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Total people with VWD	B28. VWD HIV infection	B29. VWD HCV infection
Latvia	124	0		68	0	
Lesotho	23	0		1	0	
Lithuania	147		39	134		2
Macedonia	280		47	40		1
Malaysia	1,065	2	136	386	0	1
Mexico	3,821	26	98	104	1	2
Nepal	242		2			
Netherlands	1,483					
New Zealand	362	4	150	134	0	9
Nicaragua	227	1	97			
Oman	85	0	5	253	0	
Palestine	127	0	8	5	0	0
Panama	231	17	21	323	0	1
Peru	456	150	150	38	36	36
Philippines	923	0	13			
Romania	1,510	13	900	320	0	
Saudi Arabia	183	31	88			
Senegal	111	0	2	5	0	0
Serbia	456	17	129	217	2	11
Singapore	204	0	65	58	0	2
Slovak Republic	535	0	159	411	0	23
Slovenia	192	7	89	115		6
South Africa	1,715	55	142	511	0	1
Spain	1,920	572	942	683	31	131
Sudan	459	1	23	54	0	3
Sweden	798	35	235	1,459	0	
Thailand	800	5	54		0	1
Tunisia	270	16	0			
United Kingdom	6,061	360	2,538			
United States	15,904	1,871	5,922	11,974	25	425
Uzbekistan	1,138	2	292	86		5
Venezuela	1,808	87	325	698	9	26
Viet Nam	1,231	1	129			
TOTAL	**108,666**	**6,383**	**31,707**	**33,110**	**187**	**1,752**

Healthcare System

(**HTC** means Hemophilia Treatment Centre, see definition in glossary, page 42.)

Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C21. HCV compensation	C27. HIV compensation
Albania	3,619,778	1	100	no	no
Algeria	33,769,669	10		no	
Argentina	40,677,348	22	1,350	no	yes
Armenia	2,968,586	1	164	yes	yes
Australia	20,600,856	15	1,760	no	yes
Austria	8,205,533	6		no	yes
Azerbaijan	8,177,717	1		no	no
Bahrain	718,306	1	20	no	no
Bangladesh	153,546,901	44	8,172	no	no
Belarus	9,685,768	0	0	no	no
Belgium	10,403,951	7		no	yes
Bosnia-Herzegovina	4,590,310			no	no
Brazil	191,908,598	30	11,355	no	no
Bulgaria	7,262,675	6	500	no	yes
Cambodia	14,241,640	2	43	no	no
Cameroon	18,467,692	1	36	no	no
Canada	33,212,696	25	3,030	yes	yes
China	1,330,044,605	14			
Colombia	45,013,674	8	1,400	no	no
Costa Rica	4,195,914	1	120-130	no	yes
Croatia	4,491,543	4	477	no	no
Cuba	11,423,952	16	370	no	no
Denmark	5,484,723	2	888	no	yes
Dominican Republic	9,507,133	1	197	no	no
Ecuador	13,927,650	7	180	no	no
Egypt	81,713,517	7	1,500	no	no
Eritrea	5,028,475	1	10	no	no
Finland	5,244,749	1		no	no
France	64,057,790	40	5,080	no	yes
Georgia	4,630,841	3	88	no	no
Germany	82,369,548			no	yes
Greece	10,722,816	4	470	no	no
Guatemala	13,002,206	1		no	yes
Honduras	7,639,327	2	160	no	no

Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C21. HCV compensation	C27. HIV compensation
Hungary	9,930,915	36	all	yes	yes
Iceland	304,367	1	50	no	no
India	1,147,995,898	60	almost all	no	yes
Indonesia	237,512,355	13	1,167	no	no
Iran	65,875,223	34	6,800	yes	yes
Iraq	28,221,181			no	no
Ireland	4,156,119	4	625	yes	yes
Israel	7,112,359	3	489	no	
Italy	58,145,321	52	all	yes	yes
Japan	127,288,419	9		no	yes
Jordan	6,198,677	3		no	no
Kenya	37,953,838	2	240	no	no
Korea	49,232,844	15		no	no
Kuwait	2,596,799			no	no
Kyrgyzstan	5,356,869	6		no	no
Latvia	2,245,423	2	130	yes	
Lesotho	2,128,180	1	12		
Lithuania	3,565,205	4		no	no
Macedonia	2,061,315	1		no	no
Malaysia	25,274,133	43	550	no	no
Mexico	109,955,400	75	3,801	no	no
Moldova	4,324,450			no	
Mongolia	2,996,081	3	55	no	no
Nepal	29,519,114	6	245	no	no
Netherlands	16,645,313	13		no	yes
New Zealand	4,173,460	6	805	yes	yes
Nicaragua	5,785,846	1	227	no	no
Nigeria	138,283,240	0			
Norway	4,644,457	1	400	yes	yes
Oman	3,311,640	2	25-30	no	no
Pakistan	167,762,040	15	1,200	no	no
Palestine	4,149,173	6	127	no	no
Panama	3,292,693	2		no	no
Peru	29,180,899	8	746	no	no
Philippines	92,681,453	5	25-35	no	no
Poland	38,500,696	36		no	no

Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C21. HCV compensation	C27. HIV compensation
Portugal	10,676,910	7		no	yes
Qatar	928,635	2	50	no	no
Romania	22,246,862	12		no	no
Russia	140,702,094	4		no	no
Saudi Arabia	28,161,417	1	183	no	no
Senegal	12,853,259	1	111	no	no
Serbia	10,159,046	7	300	no	no
Singapore	4,608,167	3	80	no	no
Slovak Republic	5,455,407	44	430	no	
Slovenia	2,007,711	1	380	no	yes
South Africa	43,786,115	11	992	no	yes
Spain	40,491,051	34		yes	yes
Sri Lanka	21,128,773	1		no	no
Sudan	40,218,455	1	350	no	no
Sweden	9,045,389	3	679	yes	yes
Switzerland	7,581,520	11	778	no	yes
Thailand	65,493,298	33	800	no	no
Tunisia	10,383,577	4	150	no	no
Turkey	71,892,807	34	all	no	no
Ukraine	45,994,287	2		no	no
United Kingdom	60,943,912	87	20,155	yes	yes
United States	303,824,646	147	15,904	no	yes
Uruguay	3,477,778	2			
Uzbekistan	28,268,440	1	537	no	
Venezuela	26,414,815	22	2,000	no	no
Viet Nam	86,116,559	5	1,231	no	no
Zimbabwe	12,382,920	2	50	no	no

Reported Use of Factor Concentrates

Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
Albania	1,200,000	350,000					550,000	180,000
Algeria	11,095,000	401,400			0	0	0	0
Argentina	98,500,000	9,000,000	83,500,000	6,500,000	15,000,000	2,500,000		
Armenia	104,500	35,000					30,000	
Australia	93,000,000	15,300,000	26,000,000	5,800,000	6,700,000	9,500,000		
Azerbaijan	12,500,000	600,000			1,500,000		416,810	
Bangladesh	790,000	41,000	790,000	31,000	0	10,000	40,000	41,000
Belarus	2,795,000	535,000						
Belgium	60,000,000		13,000,000		47,000,000			
Bosnia-Herzegovina	2,800,000	150,000	2,800,000	150,000				
Brazil	202,000,000	36,000,000	202,000,000	36,000,000				
Bulgaria	9,180,000	300,000	9,000,000	300,000	180,000			
Cameroon					48,152		48,152	
Canada	146,125,000	34,000,000	1,125,000	5,000,000	145,000,000	29,000,000	0	0
Colombia	37,000,000	3,500,000	35,000,000	1,500,000	2,000,000	2,000,000		
Costa Rica	6,272,000	3,984,000						
Croatia							0	0
Cuba	1,069,000	35,000	1,069,000	35,000	0	0	0	0
Dominican Republic	583,240	40,000			45,000	40,000	245,660	0
Ecuador	616,285	203,250	557,190	194,400	59,095	8,850	59,095	8,850
Eritrea	24,750	0	3,750	0	21,000	0	all	
Finland							0	0
France	350,026,520	25,111,316	59,622,770	12,836,346	290,403,750	12,274,970		
Georgia	1,962,550	400,000	1,962,550	400,000	0	0	0	0
Germany	560,000,000	80,000,000						
Greece	31,240,809	4,169,480	3,157,590	258,920	28,083,219	3,910,560		
Honduras	2,910,900	25,000					10,900	25,000
Hungary	62,000,000	5,300,000	53,600,000	5,300,000	8,400,000	0	0	0
Iceland	3,408,000	0	0	0	3,408,000	0	0	0
India	5,842,407	529,450	5,842,407	529,450	0	0	0	0
Indonesia	9,000,000						90,000	11,000

Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
Iran			105,000,000	15,000,000				
Iraq							0	0
Ireland	22,338,750	8,971,000			22,338,750	8,971,000	114,000	76,000
Italy	300,000,000	50,000,000	120,000,000	20,000,000	180,000,000	30,000,000	0	0
Japan	306,600,000	38,400,000	109,100,000	38,400,000	197,500,000			
Jordan	1,675,000	200,000					50,400	14,700
Kenya			158,000				119,000	
Korea	114,628,528	8,883,000	72,915,250	1,297,000	41,713,278	7,586,000		
Kyrgyzstan	200,000	500						
Latvia	3,625,770	508,150	3,600,770	508,150	25,000		25,000	
Lesotho	145,000	0		0		0	0	0
Lithuania	5,775,000	640,000	5,775,000	640,000				
Macedonia	1,870,000	364,500	1,870,000	364,500	0	0	0	0
Malaysia	5,500,000	6,800,000	5,500,000	6,800,000	0	0	0	0
Mexico	60,000,000	11,000,000	60,000,000	11,000,000	0	0		
Moldova	66,370	0			0	0	66,370	
Nepal	196,012	15,900	588 bags plasma	352 bags cryo				
New Zealand	20,500,000	3,800,000	7,374,250	2,800,000	13,125,750	1,000,000		
Nigeria	50,000				50,000		50,000	
Oman	594,000	37,200	594,000	37,200	0	0		
Pakistan	305,979	11,154	180,000				125,979	
Palestine	1,605,964	111,675	1,605,964	111,675	0	0	50,000	0
Panama	383,250	13,800	383,250	13,800	0	0	0	
Peru	4,500,000	1,000,000	4,500,000	1,000,000			58,327	
Philippines	1,373,738	7,000	1,361,150	100,000	12,588		120,738	7,000
Poland			all	all	0	0	0	0
Portugal	33,042,250	5,725,500	17,014,000	5,218,500	16,028,250	507,000		
Romania	16,060,000	500,000	16,000,000		60,000		91,430	3,000
Russia	230,000,000	27,700,000	229,696,400	27,700,000	303,600	0		
Saudi Arabia			2,994,750	1,284,000	0	0	0	0
Senegal	56,000				30,000		26,900	
Serbia	8,662,000	621,600	8,662,000	621,000				
Singapore	3,250,000	450,000	3,241,000	45,000	9,000			

Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
Slovak Republic	21,600,000	2,600,000	21,600,000	2,600,000	0	0	0	0
Slovenia	11,672,949	646,000	7,336,599	646,000	4,009,350			
South Africa	31,312,600	4,080,000	31,312,600	4,080,000	0	0	0	0
Spain	161,929,688	27,070,313	56,670,705	9,479,295	105,245,595	17,604,405		
Sudan	3,797,900	390,250	3,772,900	390,250	25,000	0	25,000	0
Sweden	76,364,000	13,772,000	12,428,000	6,524,000	63,936,000	7,248,000	0	0
Switzerland	26,044,000	4,813,000	6,931,500	4,285,000	19,112,500	528,000		
Turkey	73,427,500	10,782,300			192,000			
Ukraine	15,000,000						100,000	0
United States	1,800,000,000		300,000,000		1,500,000,000			
Uzbekistan							49,500	
Venezuela	60,576,500	8,034,000	31,576,500	8,034,000	29,000,000			
Viet Nam	316,551	32,846	306,991	32,846	9,560		50,000	20,000
Zimbabwe	3,187,800						50,400	34,200

Factor Use Per Capita

Country	FVIII per cap	FIX per cap
Albania	0.332	0.097
Algeria	0.329	0.012
Argentina	2.421	0.221
Armenia	0.035	0.012
Australia	4.514	0.743
Azerbaijan	1.529	0.073
Bangladesh	0.005	0.0003
Belarus	0.289	0.055
Belgium	5.767	
Bosnia-Herzegovina	0.610	0.033
Brazil	1.053	0.188
Bulgaria	1.264	0.041
Canada	4.400	1.024
Colombia	0.822	0.078
Costa Rica	1.495	0.949
Cuba	0.094	0.003
Dominican Republic	0.061	0.004
Ecuador	0.044	0.015
Eritrea	0.005	0.000
France	5.464	0.392
Georgia	0.424	0.086
Germany	6.799	0.971
Greece	2.913	0.389
Honduras	0.381	0.003
Hungary	6.243	0.534
Iceland	11.197	0.000
India	0.005	0.000
Indonesia	0.038	0.000
Ireland	5.375	2.159
Italy	5.159	0.860
Japan	2.409	0.302
Jordan	0.270	0.032
Korea	2.328	0.180
Kyrgyzstan	0.037	0.00009
Latvia	1.615	0.226

Country	FVIII per cap	FIX per cap
Lesotho	0.068	0.000
Lithuania	1.620	0.180
Macedonia	0.907	0.177
Malaysia	0.218	0.269
Mexico	0.546	0.100
Moldova	0.015	0.000
Nepal	0.007	0.001
New Zealand	4.912	0.911
Nigeria	0.0004	
Oman	0.179	0.011
Pakistan	0.002	0.0001
Palestine	0.387	0.027
Panama	0.116	0.004
Peru	0.154	0.034
Philippines	0.015	0.0001
Portugal	3.095	0.536
Romania	0.722	0.022
Russia	1.635	0.197
Senegal	0.004	
Serbia	0.853	0.061
Singapore	0.705	0.098
Slovak Republic	3.959	0.477
Slovenia	5.814	0.322
South Africa	0.715	0.093
Spain	3.999	0.669
Sudan	0.094	0.010
Sweden	8.442	1.523
Switzerland	3.435	0.635
Turkey	1.021	0.150
Ukraine	0.326	
United States	5.924	
Venezuela	2.293	0.304
Vietnam	0.004	0.0004
Zimbabwe	0.257	

Sample Survey Questionnaire

A. National Hemophilia Organization

A1. Organization name	
A2. Address	
A3. City	
A4. State, Province, Region, Prefecture, County	
A5. Postal/ZIP Code	
A6. Country	
A7. Phone	
A8. Fax	
A9. E-mail	
A10. Website	

B. Population Statistics

(Please DO NOT estimate or guess)	**Number**	**Not known**
B1. Number of identified people with **hemophilia A** and **B** (PWH)		☐
B2. Number of identified people with **von Willebrand disease** (VWD)		☐
B3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		☐

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

B4a. What is the source of the numbers provided for this survey?	**Check one** ☐ Hemophilia **registry** of PWH and other inherited bleeding disorders in your country. **(If you have a computer-based registry, please answer questions B4b to B4k.)** ☐ Information provided by your country's hemophilia treatment centres ☐ Other (Describe):
B4b. How do you collect patient data for your registry?	☐ National computerized database ☐ Annual survey of treatment centres ☐ Other (please describe):
B4c. What kind of software does your database use?	☐ Custom designed software ☐ Microsoft Access ☐ Other commercial software (please describe):
B4d. Is your national database networked or is it located on one server or computer?	☐ Networked

	☐ One location
B4e. Is your database updated throughout the year or only once per year?	☐ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
B4f. Who updates the database?	☐ Doctors update the database ☐ Patient organization updates the database ☐ Hospitals or clinics update the database ☐ Other (please describe):
B4g. Please indicate the objectives of registry.	☐ Managing care (tracking individual patient treatment) ☐ Distribution of treatment products ☐ Research ☐ Monitoring health outcomes (viral transmissions, other complications) ☐ Other (please describe):
B4h. Who owns the database? (Who paid for and maintains the software?)	☐ Patient organization ☐ Government ☐ Clinic or hospital ☐ Other (please describe):
B4i. Confidentiality: Who owns the information in the database?	☐ Patients ☐ Government ☐ Clinic or hospital ☐ Other (please describe):
B4j. Confidentiality: Is the information in the database anonymous?	☐ Yes ☐ No
B4k. Is your database software available for distribution? (that is, could you share your software with organizations that do not yet have registries?)	☐ Yes ☐ No

Age distribution of people with Hemophilia and von Willebrand disease

Age group	Number with hemophilia	Number with VWD
B6. 0 - 13 years old		
B7. 14 - 18 years old		
B8. 19 years old and over		
B9. No age data	☐	☐

Type of hereditary bleeding disorder

Diagnosis	Total	Male	Female	No data
B10. Hemophilia A				☐
B11. Hemophilia B				☐
B12. Hemophilia, type unknown				☐
B13. von Willebrand disease				☐
B14a. Other hereditary bleeding disorders: Factor I deficiency				☐

B14b. Other hereditary bleeding disorders: Factor II deficiency				☐
B14c. Other hereditary bleeding disorders: Factor V deficiency				☐
B14d. Other hereditary bleeding disorders: Factor V+VIII deficiency				☐
B14e. Other hereditary bleeding disorders: Factor VII deficiency				☐
B14f. Other hereditary bleeding disorders: Factor X deficiency				☐
B14g. Other hereditary bleeding disorders: Factor XI deficiency				☐
B14h. Other hereditary bleeding disorders: Factor XIII deficiency				☐
B14j. Other hereditary bleeding disorders: type unknown				☐
B14i.1 Platelet disorders: Glanzmann's thrombasthenia				☐
B14i.2 Platelet disorders: Bernard Soulier Syndrome				☐
B14i.3 Platelet disorders: other or unknown				☐

Number of identified people with hemophilia by diagnosis of severity

Type of hemophilia	Mild	Moderate	Severe	No Data
B15a. Hemophilia A				☐
B16a. Hemophilia B				☐

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

Type of hemophilia	Number with current inhibitors	No Data
B15b. Hemophilia A		☐
B16b. Hemophilia B		☐

HIV and hepatitis C testing among living people with hemophilia

Infectious Disease	Number of people infected	No Data
B26. HIV		☐
B27. Hepatitis C		☐

HIV and hepatitis C testing among living people with von Willebrand disease

Infectious Disease	Number of people infected	No Data
B28. HIV		☐
B29. Hepatitis C		☐

Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2007)

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
B30. Bleeding			
B31. HIV			
B32. Liver disease			
B33. Other causes			

C. Hemophilia Care System in Your Country

C1. How many **hemophilia treatment centres** are there in your country?	
C2. Number of hemophilia patients regularly cared for by all these hemophilia treatment centres:	

Compensation for HCV infection

C21. Has there been compensation for HCV infection due to blood products in your country? **If YES, please answer the following questions:**		Yes	☐
		No	☐
C22. Who paid the compensation?		Government	☐
		Private companies	☐
		Other	☐
C23. How much was paid to each individual that was compensated?			
C24. What percentage of people with hemophilia infected with HCV were compensated?			
C25. How is the compensation paid?	One payment ☐	other ☐ (please describe):	
C26. What years when patients were infected does the compensation apply to?		Start	Finish

Compensation for HIV infection

C27. Has there been compensation for HIV infection due to blood products in your country? **If YES, please answer the following questions:**		Yes	☐
		No	☐
C28. Who paid the compensation?		Government	☐
		Private companies	☐
		Other	☐
C29. How much was paid to each individual that was compensated?			
C30. What percentage of people with hemophilia infected with HIV were compensated?			
C31. How is the compensation paid?	One payment ☐	other ☐ (please describe):	
C32. What years does the compensation apply to?		Start	Finish

D. The Cost and Use of Factor Concentrates

Annual usage of factor concentrates	Factor VIII	Factor IX	Not known
D1. How many international units (IU) of factor concentrates were used in your country in 2007?			☐
D2. How many international units of **plasma-derived** concentrates were used in your country in 2007?			☐
D3. How many international units of **recombinant** concentrates were used in your country in 2007?			☐
D4. How many international units were **humanitarian aid**?			☐

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 cases of von Willebrand disease and mild hemophilia A. It is administered intravenously by subcutaneous injection or by intranasal spray.

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

Glanzmann's thrombasthenia: A severe congenital bleeding disorder in which the platelets lack glycoprotein Iib/IIIa, the blood platelet count is normal, but their function is very abnormal.

Hemophilia A: A condition resulting from factor VIII deficiency, also known as classical hemophilia.

Hemophilia B: A condition resulting from factor IX deficiency, also known as Christmas disease.

Hemophilia treatment centre: A specialized medical centre that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders.

HIV: Human immunodeficiency virus. The virus that causes AIDS.

Identified person: A living person known to have hemophilia, von Willebrand disease, or another bleeding disorder.

Inhibitors: A PWH has inhibitors when their body's immune system attacks the molecules in factor concentrate, rendering it ineffective.

International Unit (IU): A standardized measurement of the amount of factor VIII or IX contained in a vial. Usually marked on vials as 250 IU, 500 IU, or 1000 IU.

Mild hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity between 6 to 24% of normal activity in the bloodstream.

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.

Severe hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity of less than 1 % 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.

von Willebrand disease: An inherited bleeding disorder resulting from a defect or deficiency of von Willebrand factor.

VWD: von Willebrand disease.

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