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World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2008

Report on the Annual Global Survey 2008 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 2008

Report on the Annual Global Survey 2008 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 2008 survey is the tenth WFH survey. This report uses data for the years 2004, 2005, 2006, 2007 and 2008. 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 12. The survey includes data on more than 218,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 108 countries. Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed. The survey questionnaire is included at the end of this report. 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 4 and 5 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 6 to 11 use data from the 2008, 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. Countries that are part of the WFH's Global Alliance for Progress (GAP) program (Azerbaijan, Belarus, Ecuador, Jordan, Lebanon, Mexico, Russia, Thailand, Tunisia, China, and Syria) report more frequently than once per year, in these cases the most up-to-date numbers are used. This report provides information on the annual usage of treatment products for 2008 or 2007. 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) Countries with small populations can appear to have too many identified patients. Countries submitting data to the WFH range in population from 300,000 to over a billion. With a small denominator (total population), just a few extra identified patients (the numerator) can create the appearance of huge percentage differences between expected and identified patients when really there are only a few more patients than expected.

c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they don't require treatment. In countries with different health care systems, it is likely that patients that do not require treatment will not be identified.

d) Definitions may vary from country to country. Countries may use different definitions to diagnose mild hemophilia and other disorders.

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

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

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

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



2008 WFH Global Survey Summary

Demographics

Number of countries in this survey: **108**

Percentage of world population covered by 2008 survey report: **91%**

Number of people identified with hemophilia A and B (question B1): **148,971**

Number of people identified with VWD (question B2): **52,330**

Number of people identified with other bleeding disorders (question B3): **21,510**

Total number of people with bleeding disorders identified: **219,699**

Number of people with hemophilia A (question B10): **108,402**

Number of people with hemophilia B (question B11): **21,961**

Number of countries using national registries to report these numbers: **61**

Number of hemophilia A patients with clinically identified inhibitors: **3,987**

Number of hemophilia B patients with clinically identified inhibitors: **278**

Reported number of PWH infected with HIV: **5,541**

Reported number of PWH infected with HCV: **28,519**

Reported number of patients with VWD infected with HIV: **105**

Reported number of patients with VWD infected with HCV: **1,479**

Factor usage

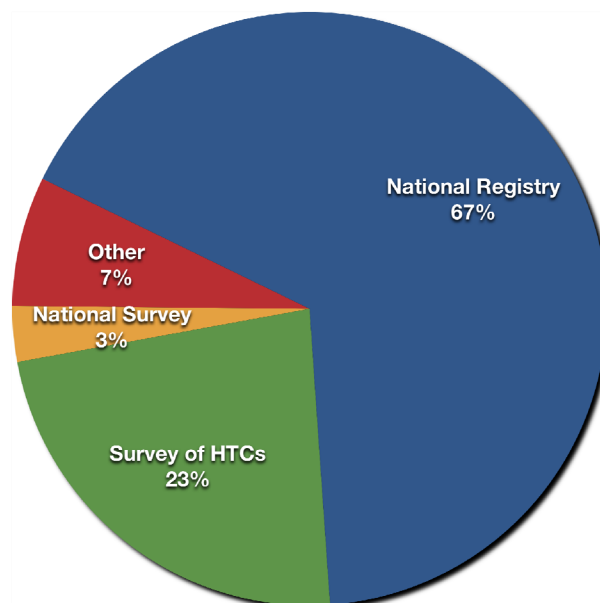
Mean global per capita factor VIII usage: **1.25 IU** (83 countries reporting)

Mean global per capita factor IX usage: **0.21 IU** (64 countries)

Total reported annual global consumption of factor VIII concentrates: **5,470,640,526 IU**

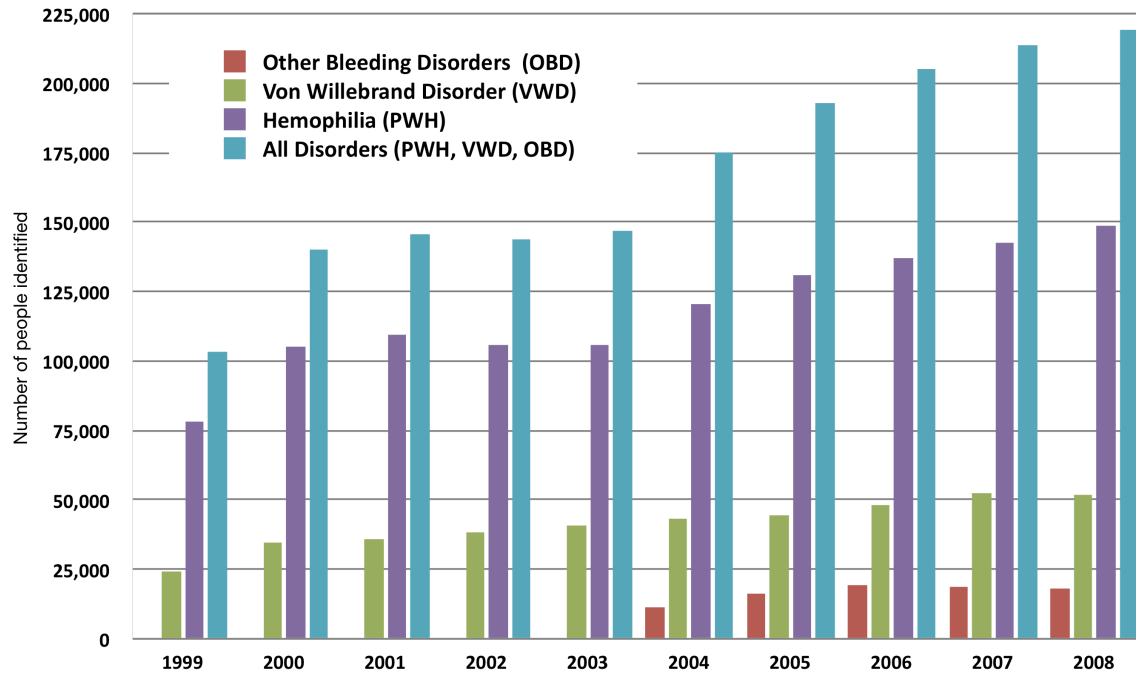
Total reported annual global consumption of factor IX concentrates: **823,496,440 IU**

Data sources





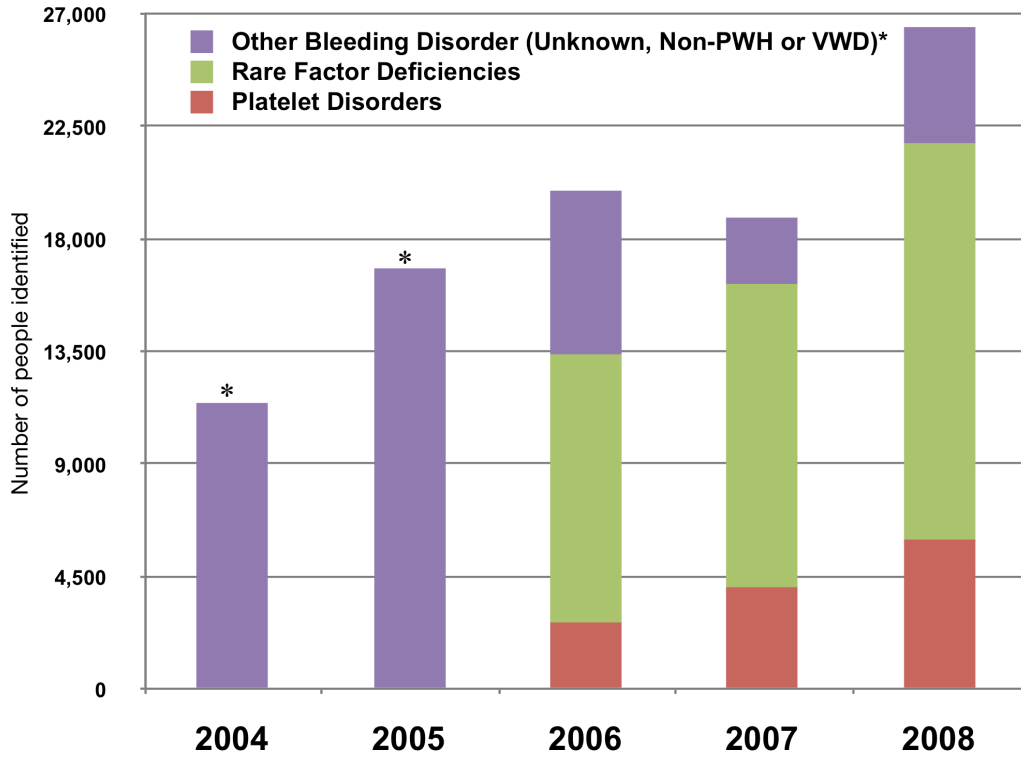
A. Identified patients – all disorders



B. Identified people with Von Willebrand Disease

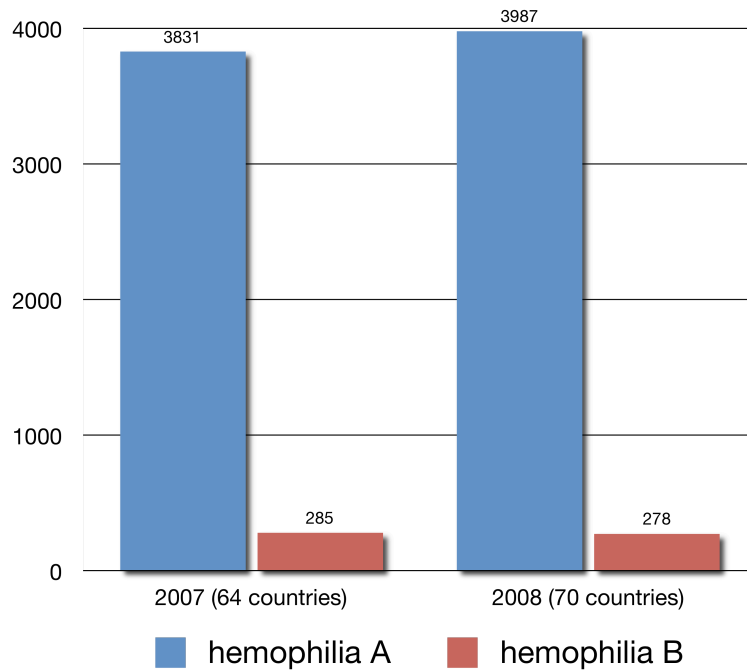


C. Other bleeding disorders

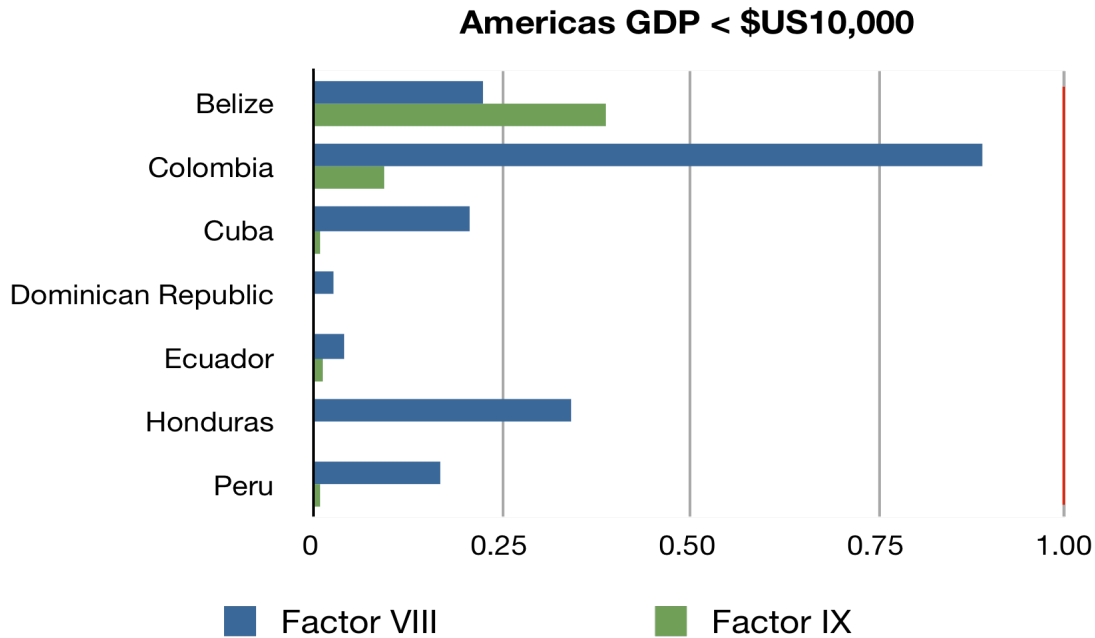
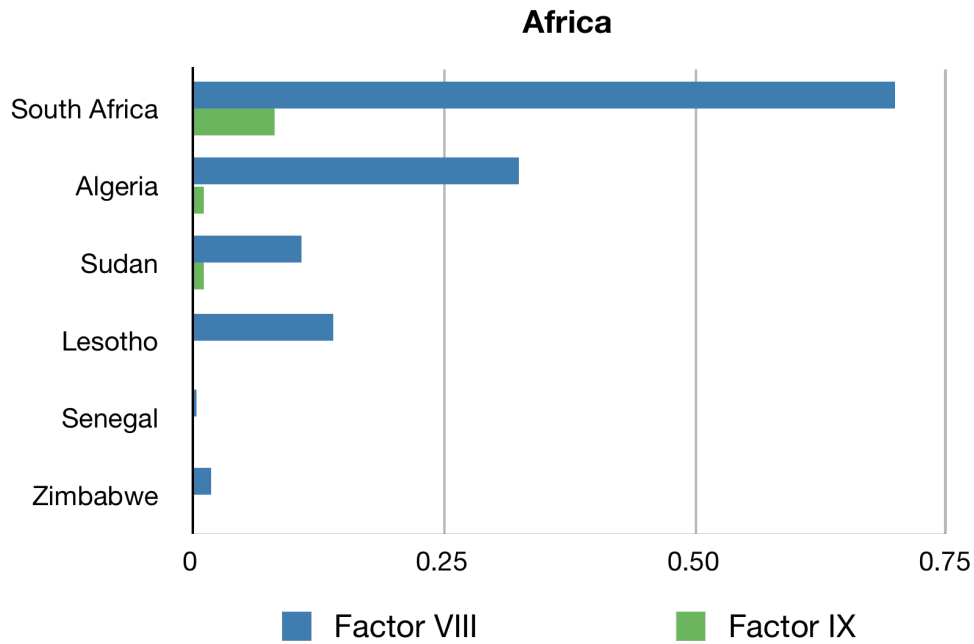


* In 2004 and 2005 the survey did not differentiate the other bleeding disorders so the totals for those years would include rare factor deficiencies.

D. Patients with current inhibitors

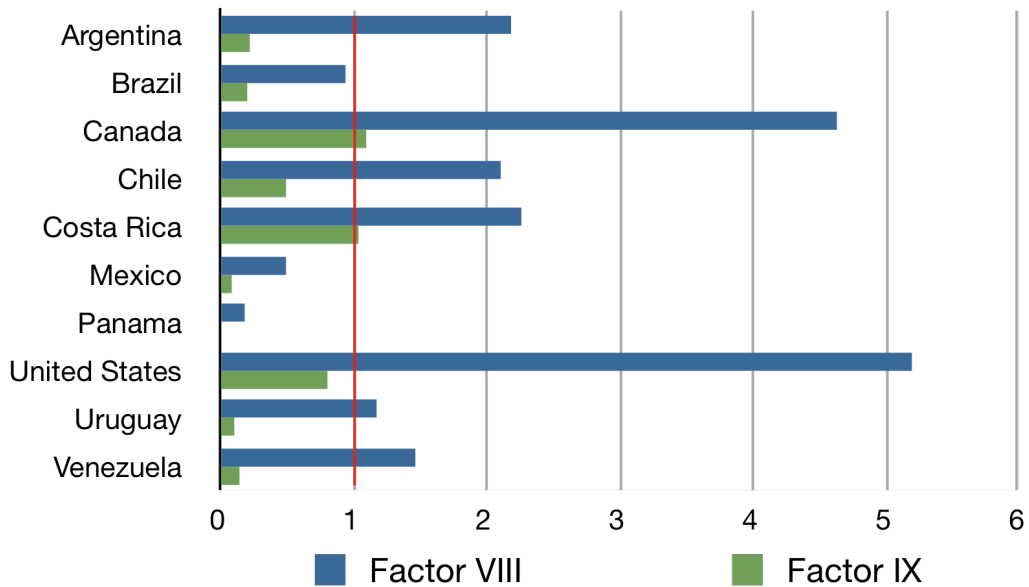


E. Per capita factor use – regional comparisons of IU/total population.

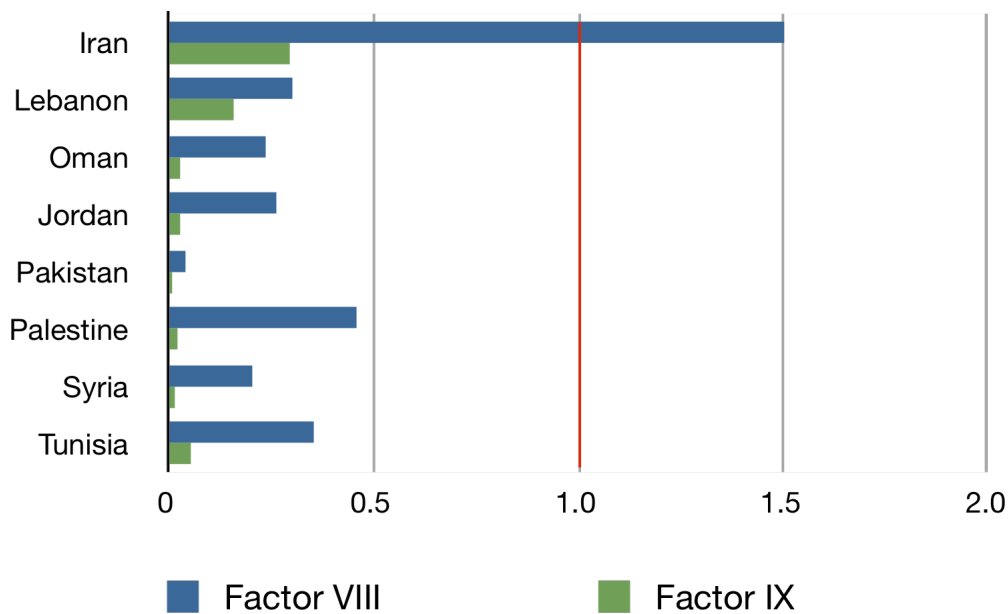


PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

Americas GDP > \$US10,000

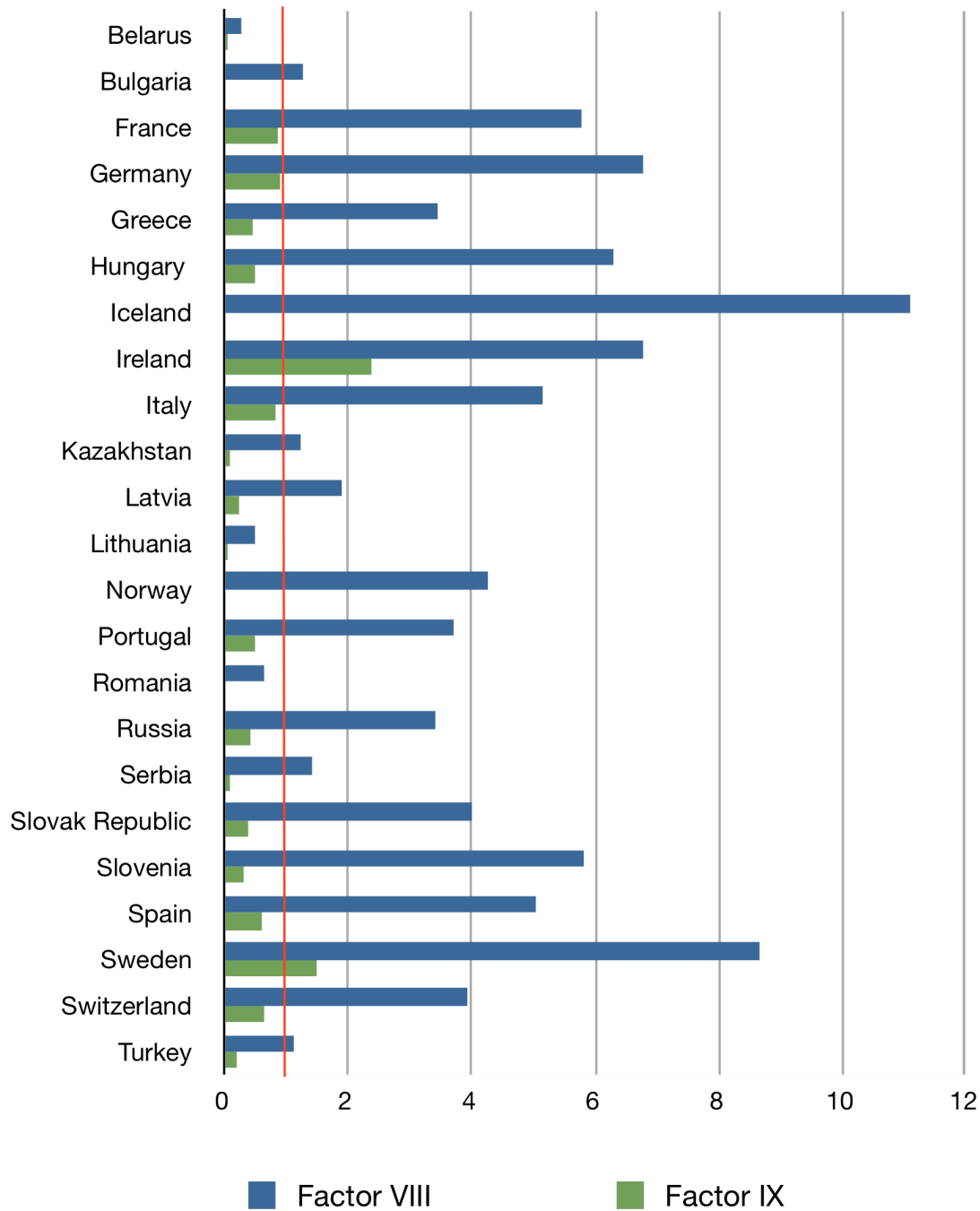


Eastern Mediterranean

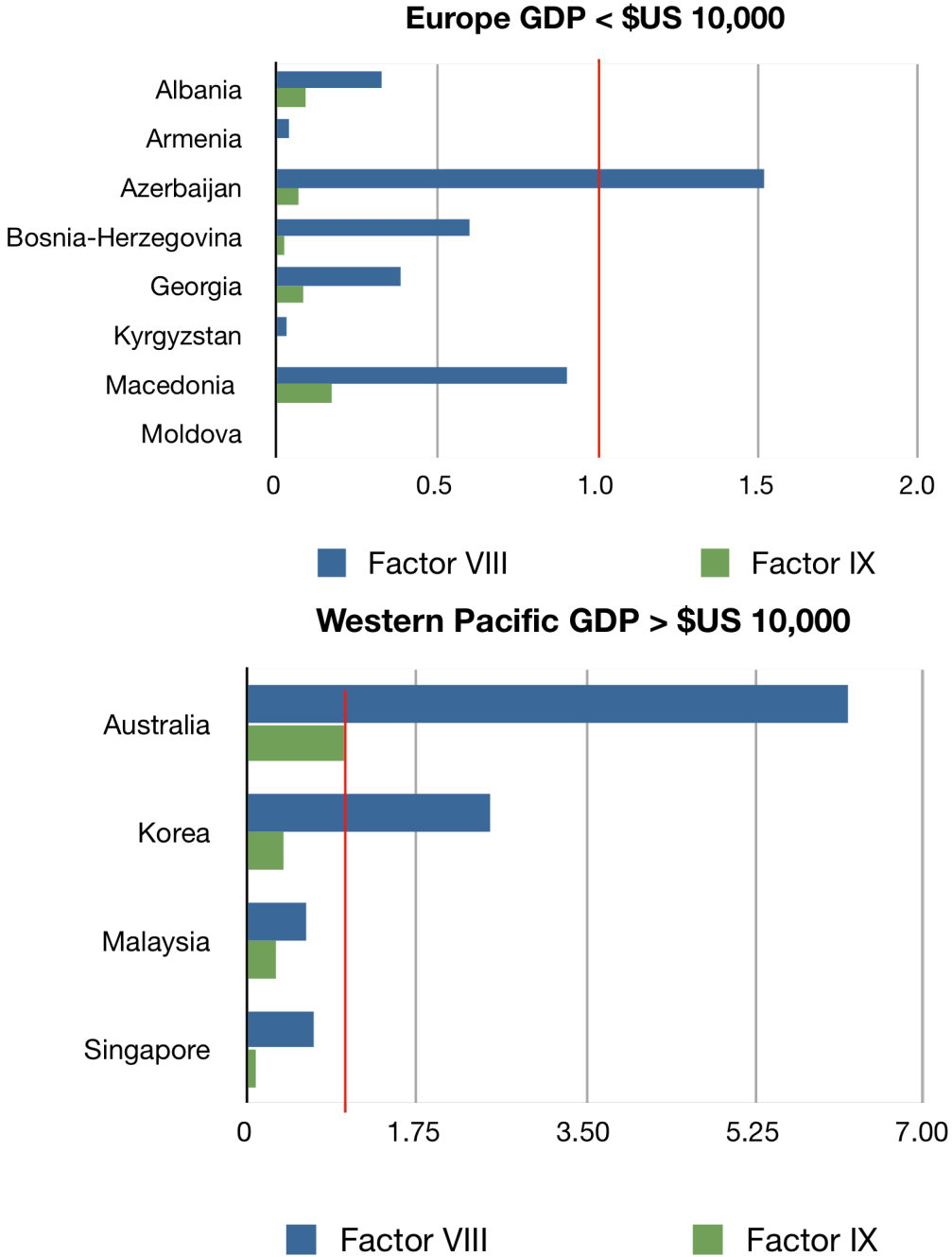


PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

Europe GDP > \$US 10,000

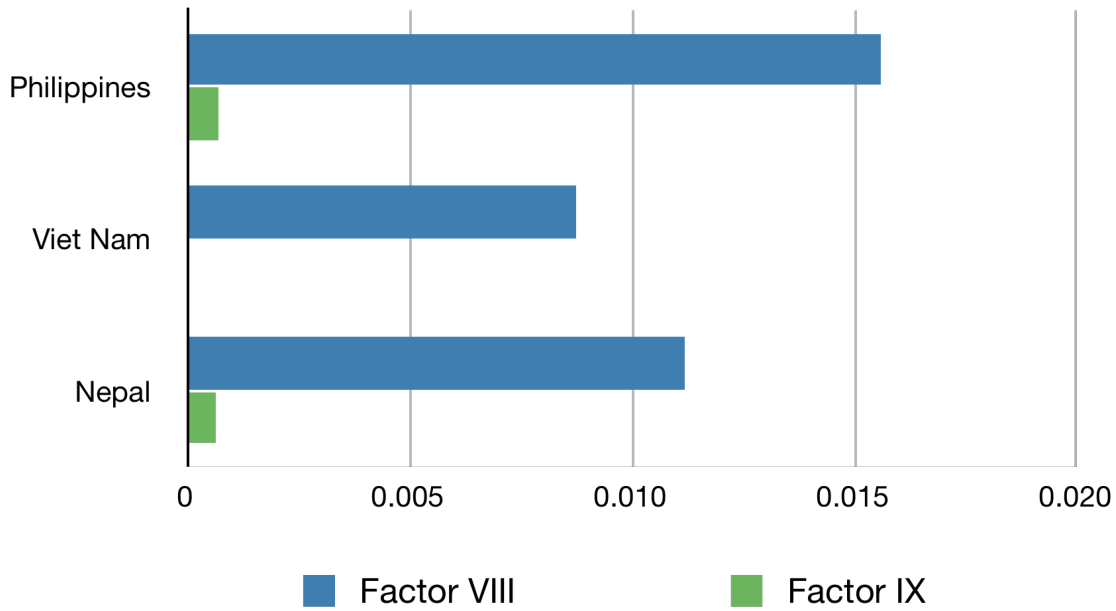


PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

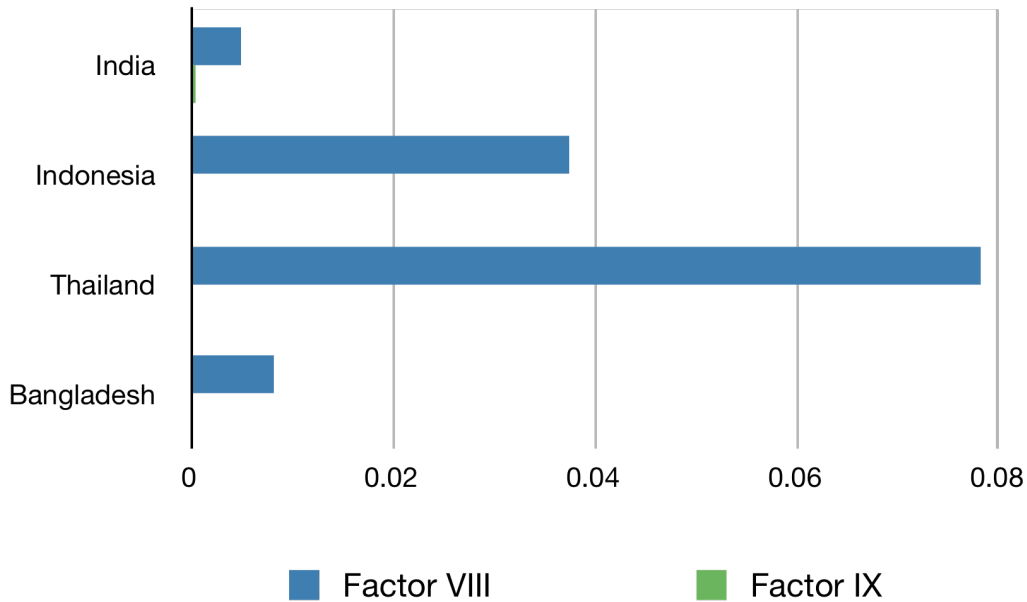


PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

Western Pacific GDP < \$US 10,000



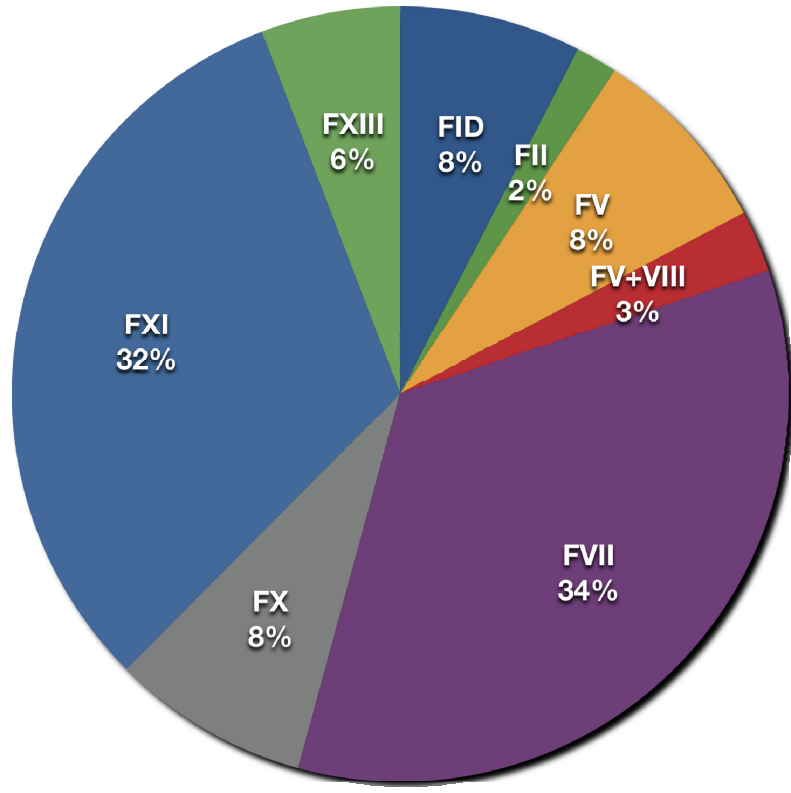
Southeast Asia



PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

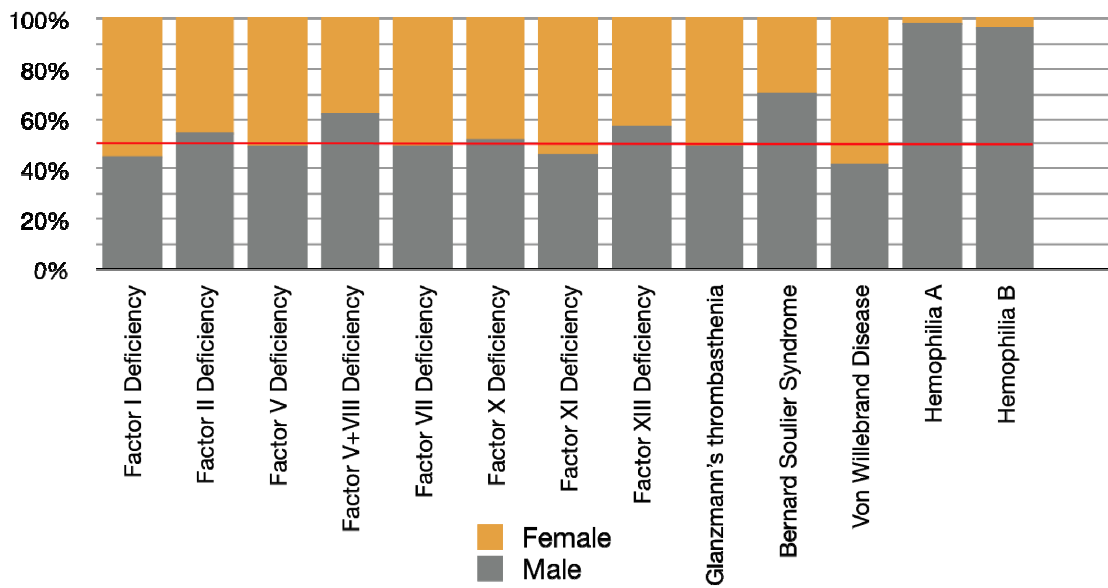
F. The graph below is based on data from 81 countries.

Distribution of rare factor deficiencies



G. The graph below shows the proportion of male and female patients for the all bleeding disorders. The red line indicates 50%. (See gender data on page 20.) These data are from the 72 countries that provided gender breakdowns.

Gender breakdown





Countries included in the 2008 WFH Global Survey Report

(Please note: the year indicates the year the submitted data applies to. Not all of our members are able to submit data every year. For the 2008 Survey report, 72 countries submitted data for 2008. The data used from other years is as follows. 2007: 20 countries, 2006: 8 countries, 2005: 3 countries, 2004: 4 countries, 2003: 1 country.)

1. Albania	2007	36. France	2008	73. Norway	2008
2. Algeria	2007	37. Georgia	2008	74. Oman	2008
3. Argentina	2008	38. Germany	2008	75. Pakistan	2008
4. Armenia	2008	39. Greece	2008	76. Palestine	2008
5. Australia	2008	40. Guatemala	2005	77. Panama	2008
6. Austria	2008	41. Honduras	2008	78. Peru	2008
7. Azerbaijan	2007	42. Hungary	2008	79. Philippines	2008
8. Bahrain	2007	43. Iceland	2007	80. Poland	2008
9. Bangladesh	2008	44. India	2007	81. Portugal	2008
10. Belarus	2006	45. Indonesia	2007	82. Qatar	2006
11. Belgium	2008	46. Iran	2008	83. Romania	2008
12. Belize	2004	47. Iraq	2008	84. Russia	2008
13. Bosnia-Herzegovina	2006	48. Ireland	2008	85. Saudi Arabia	2007
14. Brazil	2008	49. Israel	2008	86. Senegal	2008
15. Bulgaria	2006	50. Italy	2007	87. Serbia	2008
16. Cambodia	2008	51. Jamaica	2004	88. Singapore	2006
17. Cameroon	2008	52. Japan	2008	89. Slovak Republic	2008
18. Canada	2008	53. Jordan	2006	90. Slovenia	2007
19. Chile	2008	54. Kazakhstan	2008	91. South Africa	2008
20. China	2007	55. Kenya	2007	92. Spain	2008
21. Colombia	2008	56. Korea	2008	93. Sri Lanka	2007
22. Costa Rica	2008	57. Kuwait	2005	94. Sudan	2008
23. Cote d'Ivoire	2008	58. Kyrgyzstan	2007	95. Sweden	2008
24. Croatia	2007	59. Latvia	2008	96. Switzerland	2008
25. Cuba	2008	60. Lebanon	2008	97. Syria	2008
26. Cyprus	2004	61. Lesotho	2008	98. Thailand	2008
27. Czech Republic	2008	62. Lithuania	2008	99. Tunisia	2008
28. Denmark	2008	63. Macedonia	2006	100. Turkey	2008
29. Dominican Republic	2008	64. Malaysia	2008	101. Ukraine	2007
30. Ecuador	2007	65. Mexico	2008	102. United Kingdom	2007
31. Egypt	2008	66. Moldova	2008	103. United States	2008
32. El Salvador	2004	67. Mongolia	2007	104. Uruguay	2007
33. Eritrea	2008	68. Nepal	2008	105. Uzbekistan	2008
34. Estonia	2003	69. Netherlands	2008	106. Venezuela	2008
35. Finland	2008	70. New Zealand	2008	107. Viet Nam	2008
		71. Nicaragua	2006	108. Zimbabwe	2008
		72. Nigeria	2005		



Population Statistics

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.)

Country	Population ¹	B1. Number of PWH	B2. Number of people with vWD	B3. Number of people with OBD
Albania	3,639,453	265		
Algeria	34,178,188	1,291	109	
Argentina	40,913,584	2,031	353	
Armenia	2,967,004	208	5	10
Australia	21,262,641	1,760	1,308	629
Austria	8,210,281	387		
Azerbaijan	8,238,672	846	218	40
Bahrain	727,785	20		4
Bangladesh	156,050,883	376		6
Belarus	9,648,533	559		
Belgium	10,414,336	908	1,081	126
Belize	307,899	14	3	1
Bosnia-Herzegovina	4,613,414	140	30	
Brazil	198,739,269	8,172	2,333	316
Bulgaria	7,204,687	572	69	27
Cambodia	14,494,293	45	1	2
Cameroon	18,879,301	75	1	2
Canada	33,487,208	3,156	3,236	1,279
Chile	16,601,707	1,197		
China	1,338,612,968	5,126	227	
Colombia	45,644,023	1,658	168	147
Costa Rica	4,253,877	186		9
Cote d'Ivoire	20,617,068	36	1	6
Croatia	4,489,409	477	282	139
Cuba	11,451,652	390	61	861
Cyprus	796,740	103	12	5
Czech Republic	10,211,904	850		
Denmark	5,500,510	438	436	122
Dominican Republic	9,650,054	237	88	39
Ecuador	14,573,101	393	50	13
Egypt	83,082,869	5,139	439	912
El Salvador	7,185,218	254	15	7
Eritrea	5,647,168	46		
Estonia	1,299,371	39	33	3
Finland	5,250,275	313	2,788	39
France	64,057,792	4,779	272	215

¹ Population data source: CIA World Factbook, 2008

Country	Population ¹	B1. Number of PWH	B2. Number of people with vWD	B3. Number of people with OBD
Georgia	4,615,807	250	17	8
Germany	82,329,758	4,000	745	
Greece	10,737,428	902	670	215
Guatemala	13,276,517	123	14	72
Honduras	7,792,854	203	5	4
Hungary	9,905,596	1,012	1,335	333
Iceland	306,694	64	96	
India	1,166,079,217	13,448		
Indonesia	240,271,522	1,167	27	
Iran	66,429,284	4,729	876	1,557
Iraq	28,945,657	756	153	161
Ireland	4,203,200	613	918	510
Israel	7,233,701	500		
Italy	58,126,212	3,270	1,650	700
Jamaica	2,825,928	108	16	13
Japan	127,078,679	5,127	892	452
Jordan	6,342,948	248		45
Kazakhstan	15,399,437	1,360	460	108
Kenya	39,002,772	461	22	
Korea	48,508,972	1,806	93	76
Kuwait	2,691,158			
Kyrgyzstan	5,431,747	206		
Latvia	2,231,503	127	80	1
Lebanon	4,017,095	165	63	37
Lesotho	2,130,819	18	1	0
Lithuania	3,555,179	146	120	44
Macedonia	2,066,718	280	40	
Malaysia	25,715,819	1,103	412	393
Mexico	111,211,789	3,826	165	11
Moldova	4,320,748	237	3	
Mongolia	3,041,142	49	2	4
Nepal	28,563,377	266		7
Netherlands	16,715,999	1,452	263	64
New Zealand	4,213,418	332	109	12
Nicaragua	5,891,199	227	37	5
Nigeria	149,229,090	42	3	4
Norway	4,660,539	397	858	37
Oman	3,418,085	93	262	296
Pakistan	176,242,949	1,285	268	187
Palestine	4,013,126	131	7	56
Panama	3,360,474	263	346	16

Country	Population ¹	B1. Number of PWH	B2. Number of people with vWD	B3. Number of people with OBD
Peru	29,546,963	503	100	21
Philippines	97,976,603	984	28	
Poland	38,482,919	2,520	1,079	563
Portugal	10,707,924	607	51	52
Qatar	833,285	112	7	62
Romania	22,215,421	1,638	349	56
Russia	140,041,247	6,713	1,208	933
Saudi Arabia	28,686,633	183		
Senegal	13,711,597	119	6	3
Serbia	7,379,339	471	226	16
Singapore	4,657,542	204	58	85
Slovak Republic	5,463,046	545	437	704
Slovenia	2,005,692	192	115	73
South Africa	49,052,489	1,783	522	208
Spain	40,525,002	1,932	690	199
Sri Lanka	21,324,791	252	2	
Sudan	41,087,825	618	54	52
Sweden	9,059,651	1,017	1,523	
Switzerland	7,604,467	631	106	56
Syria	20,178,485	220	15	6
Thailand	65,905,410	955	59	39
Tunisia	10,486,339	250	76	112
Turkey	76,805,524	3,419	446	418
Ukraine	45,700,395	2,600		
United Kingdom	61,113,205	6,061	7,852	4,999
United States	307,212,123	16,243	11,852	1,616
Uruguay	3,494,382	152		
Uzbekistan	27,606,007	1,142	88	35
Venezuela	26,814,843	1,923	698	611
Viet Nam	86,967,524	1,393	33	204
Zimbabwe	11,392,629	311	3	
Totals:	6,039,076,595	148,971	52,330	21,510

Distribution of reported bleeding disorders by country

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.)

Country	B10. Hemophilia A Total	B11. Hemophilia B Total	B12. Hemophilia type unknown Total	B13. vWD Total	B14A. FID Total	B14B. FIID Total	B14C. FVD Total	B14D. FV+VIII Total	B14E. FVIIID Total	B14F. FXD Total	B14G. FXID Total	B14H. FXIIID Total	B14J. Bleeding Dis.: Type Unknown Total	B14I.1 Platelet dis.Glanz. Total	B14I.2 Plat. Dis. Bernard S. Total	B14I.3 Plat. Dis. Other/Un. Total
Albania (2007)	238	27							2							
Algeria (2007)	962	200	120													
Argentina	1,777	254		353												
Armenia	186	16	1	5	3		1	1		3	2		1	1		
Australia	1,410	350		1,308			7		36	6	92	14	10			91
Austria	337	50														
Azerbaijan (2007)	810	36	32	218		3			3	1			6		1	4
Bahrain (2007)	19	1							1	3				2	1	
Bangladesh	325	51	5									1				
Belarus (2006)	463	96														
Belgium				1,082			16		39	4	59	2		16		
Belize (2004)	11	3		3												
Bosnia-Herzegovina (2006)	100	10		30												
Brazil	6,881	1,291		2,333	11	1	35	12	101	20	39	16	219	57	1	
Bulgaria (2006)	507	65	2	69	10	1			10	3	1					
Cambodia	40	5		1												2
Cameroon	71	4		1										1		
Canada	2,543	613		3,236	73	8	48	4	214	29	288	49	24	51	25	462
Chile	1,042	155														
Colombia	1,255	272	131	168	17	9	8	2	17	1	8	7	15	5	2	22
Costa Rica	157	29							2	4	1	2				
Cote d'Ivoire	32	5		1							1					
Croatia (2007)	385	92	0	282	6	0	12	3	48	3	19	7	3			17
Cuba	323	67		61	1	1					6	4		2		867
Cyprus (2004)	52	61		12												
Czech Republic	730	120														
Denmark	357	81		436		1	1		16	7	5	9		9	11	36
Dominican Republic	204	33		88				1	4	10		1	21	2		
Ecuador (2007)	354	39		50	1	0	1	0	2	1	3	1	2			
Egypt	129	37		25	8	1	4	1	4	12	1	4		20		

Country	B10. Hemophilia A Total	B11. Hemophilia B Total	B12. Hemophilia type unknown Total	B13. vWD Total	B14A. FID Total	B14B. FIID Total	B14C. FVD Total	B14D. FV+VIII Total	B14E. FVIID Total	B14F. FXD Total	B14G. FXID Total	B14H. FXIID Total	B14J. Bleeding Dis.: Type Unknown Total	B14I.1 Platelet dis.Glanz. Total	B14I.2 Plat. Dis. Bernard S. Total	B14I.3 Plat. Dis. Other/Un. Total
El Salvador (2004)	229	25		15												
Eritrea	41	5														
Estonia (2003)	36	3		33												
Finland	245	68	0	2,788	12	2	5	0	6	0	1	13		0	20	
France	3,929	850		850	29	1	26	7	89	14	84	22				
Georgia	203	39		17					2			1		2		3
Germany	4,000	745		3,100												
Greece	767	135		670	16	1	6		56	7	46	10	1	13	7	52
Guatemala (2005)	114	9		14												
Honduras	187	16	23	5					1		1	2				
Hungary	815	197		1,335	13	14	25	0	189	25	66	1		8	2	
Iceland (2007)	63	2	0	96										0	12	
India (2007)	10,982	1,939	527													
Indonesia (2007)	233	33														
Iran	3,996	733		876	87	14	82	137	260	103	69	129	32	264	37	342
Iraq	568	188		153	31		1		44	8	1	9				67
Ireland	410	203	0	918	0	0	55	0	46	67	84	3	92	9	2	147
Israel	415	85														
Italy (2007)	2,697	573	21	1,650	49	14	73	23	308	54	156	21	45			115
Jamaica (2004)	101	8	0	16												
Japan	4,211	916		892	57	6	24	6	52	15	26	57		12	2	
Jordan (2006)	202	46					1		51	3	3	6				
Kazakhstan	1,036	324		460												
Korea	1,480	326	18	93	4		2	8	19		13	4	7			
Kyrgyzstan (2007)	197	9												1		
Latvia	107	20		80					1							
Lebanon	109	29		62	21	1	4	1	1	1	3	2				3
Lesotho	18	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Lithuania	126	20		120			2		28	1	1	3				11
Macedonia (2007)	200	80		40												
Malaysia	935	168	0	412	4	2	14		55	13	45	11		37		80
Mexico	3,294	532	364	165	0	0	1	1	6	1	0	0	0	1	0	1
Moldova	224	13		3												



Country	B10. Hemophilia A Total	B11. Hemophilia B Total	B12. Hemophilia type unknown Total	B13. vWD Total	B14A. FID Total	B14B. FIID Total	B14C. FVD Total	B14D. FV+VIIIID Total	B14E. FVIIID Total	B14F. FXD Total	B14G. FXID Total	B14H. FXIIID Total	B14J. Bleeding Dis.: Type Unknown Total	B14I.1 Platelet dis.Glanz. Total	B14I.2 Plat. Dis. Bernard S. Total	B14I.3 Plat. Dis. Other/Un. Total
Mongolia (2007)	49	4		2												
Nepal	235	31				1			1	5						
New Zealand	267	65		111						1	2	3	6			
Nicaragua (2006)	205	22		37	4											
Nigeria (2005)	32	5	5	3												
Norway	301	96	0		3		2	0	23	0	0					
Oman	86	7		262	5	1	3	5	47	3	13	1	61	23	2	132
Pakistan	1,090	195	3	268	9	1	18	4	23	17	4	17	7	44	15	25
Palestine	104	27		7	11	0	2	0	0	6	0	0		36	1	
Panama	238	25		346		1			3	10				1	1	
Philippines	853	131	42	28												
Poland	2,153	367		1,079			16		173	14	28	9		16	0	
Portugal	506	101		51	2		3				7	1				
Qatar (2006)	87	25		7	2		6	1	6	2	20	1				
Romania	1,444	199	12	348	2			2	7	2	12			1		41
Russia	5,032	681		1,208												933
Serbia	403	68		226	1			1	4		4	4	1		1	
Singapore (2006)	176	28	0	58	0	0	15	0	9	0	46	3				
Slovak Republic	476	70	0	437	54	0	40	2	515	10	27	3	0	10	6	17
Slovenia (2007)	173	19		115			8		9	1	11			2		7
South Africa	1,507	278		522	7		43	4	18	10	27	6		15	23	47
Spain	1,664	268		690	18	3	13	3	23	56	48	20	3	12		
Sri Lanka (2007)	184	36	32	2												
Sudan	514	104	0	54	8	0	11	0	4	6	0	6	10	16	3	0
Sweden	815	202														
Switzerland	523	108		106	9			4		3	3	14				
Syria	185	35		15		2	1	1	1					1		
Thailand	955	103		59	1		2	1	11	1						27
Tunisia	162	38	0	76	11	0	3	5	15	1	4	13		138	6	
Turkey	2,890	529		446			15		173	55	1	21	156			1
United Kingdom (2007)	4,991	1,070		7,852	156	6	112	22	517	170	1,566	49		91	50	973
United States	12,386	3,857		11,852	94	40	139		634	80	542	87				
Uruguay (2007)	133	19														



Country	B10. Hemophilia A Total	B11. Hemophilia B Total	B12. Hemophilia type unknown Total	B13. vWD Total	B14A. FID Total	B14B. FIID Total	B14C. FVD Total	B14D. FV+VIIID Total	B14E. FVIID Total	B14F. FXD Total	B14G. FXID Total	B14H. FXIIID Total	B14J. Bleeding Dis.: Type Unknown Total	B14I.1 Platelet dis. Glanz. Total	B14I.2 Plat. Dis. Bernard S. Total	B14I.3 Plat. Dis. Other/Un. Total
Uzbekistan	1,025	117		88		7			3				33	5	1	
Venezuela	1,508	416		698	39	61	27	25	113	88	245	13		13	10	20
Viet Nam	1,180	213		33		2	2	16	4	7	2	1	11	62		97
Totals	108,402	21,961	1,338	51,686	884	205	936	303	4031	967	3736	683	765	999	223	4639

**Gender breakdowns** (72 countries reporting)

This table provides the number of males and females with each bleeding disorder. The sum of the numbers reported for male and female for each disorder may not equal the total reported here because some countries lack specific data on gender for the entire patient population.

Disorder	Total	Male	Female
Hemophilia A (B10)	79,820	77859	1817
Hemophilia B (B11)	16,976	16318	651
Hemophilia type unknown (B12)	662	636	10
Von Willebrand Disorder (B13)	44,731	16235	23207
Factor I Deficiency (B14A)	806	319	396
Factor II Deficiency (B14B)	183	61	53
Factor V Deficiency (B14C)	817	348	363
Factor V+VIII Deficiency (B14D)	303	128	82
Factor VII Deficiency (B14E)	3,608	1,563	1,630
Factor X Deficiency (B14F)	891	385	368
Factor XI Deficiency (B14G)	3,484	1,382	1,690
Factor XIII Deficiency (B14H)	635	323	254
Bleeding Disorder: Type Unknown (B14J)	666	180	165
Platelet disorders: Glanzmann's thrombasthenia (B14I.1)	977	294	310
Platelet disorders: Bernard Soulier Syndrome (B14I.2)	206	84	92
Platelet disorders: other or unknown (B14I.3)	3,577	1,211	1,944

Patients with clinically identified inhibitors

Country	B10. Hemophilia A Total	B15 b. Hemophilia A w/ clinically identified inhibitors	B11. Hemophilia B Total	B16 b Hemophilia B w/ clinically identified inhibitors
Argentina	1,777	130	254	6
Armenia	186	7	16	
Australia	1,410	58	350	4
Austria	337	37	50	0
Azerbaijan	810	4	36	
Belarus	463	29	96	
Brazil	6,881	293	1,291	10
Bulgaria	507	29	65	
Cambodia	40	0	5	0
Cameroon	71	8	4	
Canada	2,543	68	613	4
Chile	1,042	17	155	1
Colombia	1,255	57	272	6
Costa Rica	157	15	29	0
Cote d'Ivoire	32	2	5	
Cuba	323	58	67	1
Denmark	357	7	81	1
Finland	245	15	68	1
France	3,929	65	850	2
Georgia	203	2	39	0
Germany	4,000	94	745	14
Greece	767	20	135	2
Honduras	187	1	16	
Iceland	63	0	2	0
Indonesia	233	43	33	
Iran	3,996	147	733	4
Iraq	568	10	188	
Ireland	410	7	203	1
Italy	2,697	288	573	8
Japan	4,211	79	916	14
Jordan	202	18	46	0
Kazakhstan	1,036	5	324	2
Korea	1,480	59	326	9
Latvia	107	2	20	2
Lebanon	109	3	29	0
Lesotho	18	1	0	0
Lithuania	126	6	20	0
Macedonia	200	3	80	1
Malaysia	935	78	168	2
Mexico	3,294	118	532	7
Nepal	235	1	31	
New Zealand	267	24	65	0
Nicaragua	205	5	22	
Norway	301	12	96	0

Country	B10. Hemophilia A Total	B15 b. Hemophilia A w/ clinically identified inhibitors	B11. Hemophilia B Total	B16 b Hemophilia B w/ clinically identified inhibitors
Oman	86	8	7	0
Pakistan	1,090	49	195	9
Palestine	104	10	27	1
Panama	238	12	25	0
Philippines	853	11	131	2
Romania	1,444	60	199	2
Russia	5,032	152	681	3
Serbia	403	15	68	0
Singapore	176	10	28	0
Slovak Republic	476	14	70	1
Slovenia	173	4	19	
South Africa	1,507	144	278	5
Sudan	514	1	104	1
Sweden	815	24	202	5
Switzerland	523	16	108	1
Syria	185	10	35	2
Tunisia	162	7	38	0
Turkey	2,890	244	529	32
United Kingdom	4,991	100	1,070	5
United States	12,386	943	3,857	99
Uzbekistan	1,025	73	117	
Venezuela	1,508	84	416	3
Viet Nam	1,180	9	213	0
Totals	85,976	3925	18,066	273



HIV and HCV infection

Country	B1. Number of PWH	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Number of people with vWD	B28. vWD HIV infection	B29. vWD HCV infection
Albania	265	1	233			
Argentina	2,031	68	640	353	0	10
Armenia	208	0	88	5	1	2
Australia	1,760	103	643	1,308	4	70
Austria	387	119	29			
Azerbaijan	846	0	592	218		152
Bangladesh	376		1			
Belize	14	0	0	3	0	0
Brazil	8,172	312	1,667	2,333	14	168
Bulgaria	572	9	516	69	0	50
Cameroon	75	0	0	1	0	0
Canada	3,156	213	881	3,236	5	67
Colombia	1,658	15	90	168	0	4
Costa Rica	186	16	61			
Croatia	477	6	198	282	0	25
Cuba	390	4	152	61	0	18
Cyprus	103	2	13	12		
Czech Republic	850	15				
Denmark	438	27		436		
Dominican Republic	237	2		88		
Egypt	4,482	0	26	439	0	0
El Salvador	254	2		15		
Estonia	39	0	21	33	0	4
Finland	313	2		2,788		
France	4,779	430	1,617	272	14	127
Georgia	242	0	128	17	0	4
Germany	4,000	436	3,000	745		
Greece	902	68	334	670	1	19
Guatemala	123	0	26	14	0	0
Hungary	1,012	32		1,335		
Iceland	64	0	9	96	0	0
India	13,448	142				
Indonesia	1,167	0	63	27		
Iran	4,729	126	719	876	2	66
Iraq	756	0	186	153	0	28
Ireland	613	36	142	918		11
Israel	500	25	172			
Italy	3,270	220	1,156	1,650	7	69
Jamaica	108	8	36	16	1	1
Japan	5,127	796	1,165	892		
Kazakhstan	1,360	18	60	460		
Korea	1,806	21	647	93	0	4

Country	B1. Number of PWH	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Number of people with vWD	B28. vWD HIV infection	B29. vWD HCV infection
Kyrgyzstan	206		165			
Latvia	127		41	80		
Lebanon	139	0	15	63	0	1
Lithuania	146	0	39	120	0	2
Macedonia	280		47	40		1
Malaysia	1,103	2	136	412	0	1
Mexico	3,826	24	114	165	1	2
Moldova	237	0		3	0	
New Zealand	332	8	224	109	0	6
Nicaragua	227	1	97	37		
Oman	93	1	9	262		
Pakistan	1,285	2	481	268	0	62
Panama	263	15	21	346	0	1
Peru	503	8	64	100	0	3
Philippines	984	0	30	28		
Romania	1,638	13	900	349	0	
Saudi Arabia	183	31	88			
Senegal	119	0	2	6		
Serbia	471	18	50	226	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	1,783	64	180	522	0	2
Spain	1,932	462	584	690	29	106
Sudan	618	2	23	54	0	3
Sweden	1,017	35	161	1,523		
Syria	220	0	39	15	0	3
Thailand	955	10	54	59	0	1
Tunisia	200	16	112	76		
United Kingdom	6,061	360	2,538	7,852		
United States	16,243	1,095	6,046	11,852	15	312
Uzbekistan	1,142	3	300	88		5
Venezuela	1,923	89	325	698	9	26
Viet Nam	1,393	1	132	33	0	1
Totals	142,894	5,541	28,529	51,446	105	1,479



Healthcare System

Question C3: How are the majority of people with hemophilia diagnosed?

Fifty-seven countries reported on how patients are diagnosed. In over 90% of these countries, specific factor assays are used to diagnose patients. In a small group of countries clinical symptoms or clotting screening tests are still used to diagnose bleeding disorders.

Questions C4 and C5: Who pays for the medical care for the majority of people with hemophilia?

Sixty-eight countries provided data on who pays for health care and medicines. Governments cover all health care in 83% of the countries reporting. In the other 17%, patients must pay themselves or pay for private health insurance.

Number of Hemophilia Treatment Centers

The list below shows the number of Hemophilia Treatment Centers (HTCs) in each country. Some patients seek treatment at more than one center. Some centers treat all bleeding disorders.

Albania	1	Germany	32	Pakistan	12
Algeria	10	Greece	4	Palestine	6
Argentina	22	Guatemala	1	Panama	2
Armenia	1	Honduras	2	Peru	10
Australia	16	Hungary	18	Philippines	5
Azerbaijan	1	Iceland	1	Portugal	7
Bahrain	1	India	60	Qatar	2
Bangladesh	3	Indonesia	13	Romania	12
Belgium	7	Iran	10	Russia	4
Belize	3	Iraq	1	Saudi Arabia	1
Brazil	44	Ireland	4	Senegal	1
Bulgaria	6	Israel	3	Serbia	7
Cambodia	2	Italy	52	Singapore	3
Cameroon	3	Jamaica	3	Slovak Republic	44
Canada	26	Japan	9	Slovenia	1
Chile	32	Jordan	3	South Africa	12
China	14	Kenya	2	Spain	4
Colombia	10	Korea	15	Sri Lanka	1
Costa Rica	1	Kyrgyzstan	6	Sudan	1
Cote d'Ivoire	1	Latvia	2	Sweden	3
Croatia	4	Lebanon	1	Switzerland	11
Cuba	16	Lesotho	1	Syria	2
Cyprus	1	Lithuania	2	Thailand	38
Czech Republic	8	Macedonia	1	Tunisia	4
Denmark	2	Malaysia	50	Turkey	34
Dominican Republic	1	Mexico	75	Ukraine	2
Ecuador	7	Moldova	2	United Kingdom	87
Egypt	10	Mongolia	3	United States	127
El Salvador	3	Nepal	6	Uruguay	2
Eritrea	1	Netherlands	13	Uzbekistan	1
Estonia	3	New Zealand	6	Venezuela	21
Finland	8	Nicaragua	1	Viet Nam	6
France	40	Norway	1	Zimbabwe	2
Georgia	3	Oman	2		

Reported Use of Factor Concentrates: Factor VIII

Country	Population	D1A. Factor VIII total IU	Percent plasma-derived	Percent recombinant	D4A. Humanitarian Aid factor VIII	FVIII per cap
Albania	3,639,453	1,200,000			550,000	0.33
Algeria	34,178,188	11,095,000				0.32
Argentina	40,913,584	89,600,000	82%	18%		2.19
Armenia	2,967,004	137,000			30,000	0.05
Australia	21,262,641	131,984,750	13%	87%		6.21
Azerbaijan	8,238,672	12,500,000	88%	12%	416,810	1.52
Bangladesh	156,050,883	1,290,000	92%	9%	144,535	0.008
Belarus	9,648,533	2,795,000				0.29
Belize	307,899	70,000			20,000	0.23
Bosnia-Herzegovina	4,613,414	2,800,000	100%	0%		0.61
Brazil	198,739,269	190,000,000	100%	0%		0.96
Bulgaria	7,204,687	9,180,000	98%	2%		1.27
Cameroon	18,879,301	20,000	100%	0%	40,000	0.001
Canada	33,487,208	155,487,497	0%	100%		4.64
Chile	16,601,707	35,200,000	99%	1%		2.12
Colombia	45,644,023	40,700,000	87%	13%	47,200	0.89
Costa Rica	4,253,877	9,647,000	100%	0%		2.27
Cote d'Ivoire	20,617,068	2,779,010	0%	100%	2,779,010	0.13
Cuba	11,451,652	2,445,290	98%	2%	38,790	0.21
Dominican Republic	9,650,054	263,668	0%	19%	42,834	0.03
Ecuador	14,573,101	616,285	90%	10%	59,095	0.04
France	64,057,792	370,234,590	19%	81%		5.78
Georgia	4,615,807	1,817,142	100%	0%		0.39
Germany	82,329,758	560,000,000	45%	55%		6.80
Greece	10,737,428	37,434,420	8%	92%		3.49
Honduras	7,792,854	2,680,000			452,863	0.34
Hungary	9,905,596	62,550,000	75%	25%		6.31
Iceland	306,694	3,408,000	0%	100%		11.11
India	1,166,079,217	5,842,407	100%	0%		0.005
Indonesia	240,271,522	9,000,000			90,000	0.04
Iran	66,429,284	100,000,000				1.51
Ireland	4,203,200	28,564,750	2%	98%		6.80
Italy	58,126,212	300,000,000	40%	60%		5.16
Japan	127,078,679	318,600,000	31%	70%		2.51
Jordan	6,342,948	1,675,000			50,400	0.26
Kazakhstan	15,399,437	19,333,604				1.26
Kenya	39,002,772	158,000	100%	0%	119,000	0.004
Korea	48,508,972	122,370,500	54%	46%		2.52
Kyrgyzstan	5,431,747	200,000				0.04
Latvia	2,231,503	4,289,000	100%	0%		1.92
Lebanon	4,017,095	1,228,500	90%	10%	236,000	0.31
Lesotho	2,130,819	297,500				0.14
Lithuania	3,555,179	1,820,000	100%	0%		0.51
Macedonia	2,066,718	1,870,000	100%	0%		0.90
Malaysia	25,715,819	16,000,000	100%	0%		0.62

Country	Population	D1A. Factor VIII total IU	Percent plasma-derived	Percent recombinant	D4A. Humanitarian Aid factor VIII	FVIII per cap
Mexico	111,211,789	56,241,750			250,000	0.51
Moldova	4,320,748	65,000	46%	54%	65,034	0.02
Nepal	28,563,377	318,975				0.011
New Zealand	4,213,418	5,615,250	100%	0%		1.33
Nigeria	149,229,090	50,000	0%	100%	50,000	0.0003
Norway	4,660,539	20,000,000	40%	60%		4.29
Oman	3,418,085	821,500	100%	0%		0.24
Pakistan	176,242,949	7,588,440	99%	1%	7,050,480	0.04
Palestine	4,013,126	1,850,000	100%	0%		0.46
Panama	3,360,474	626,250	100%	0%		0.19
Peru	29,546,963	5,041,750	100%	0%	100,000	0.17
Philippines	97,976,603	1,526,143	67%	33%	441,987	0.02
Poland	38,482,919	2,970,000	100%	0%		0.08
Portugal	10,707,924	34,203,250	44%	56%		3.19
Romania	22,215,421	14,700,000			20,000	0.66
Russia	140,041,247	481,490,276	95%	5%		3.44
Saudi Arabia	28,686,633	2,994,750	100%	0%		0.10
Senegal	13,711,597	59,000	75%	25%	30,000	0.004
Serbia	7,379,339	10,573,750	100%	0%		1.43
Singapore	4,657,542	3,250,000	100%	0%		0.70
Slovak Republic	5,463,046	22,200,000	99%	1%		4.06
Slovenia	2,005,692	11,672,949	65%	35%		5.66
South Africa	49,052,489	34,319,300	100%	0%		0.70
Spain	40,525,002	205,107,000	40%	60%		5.06
Sudan	41,087,825	4,523,305	100%	0%		0.11
Sweden	9,059,651	78,699,000	13%	87%		8.69
Switzerland	7,604,467	30,000,000	20%	80%		3.95
Syria	20,178,485	4,200,000				0.21
Thailand	65,905,410	5,150,000	100%	0%	250,940	0.08
Tunisia	10,486,339	3,736,000	97%	3%	100,000	0.36
Turkey	76,805,524	87,078,000	95%	5%		1.13
Ukraine	45,700,395	15,000,000			100,000	0.33
United States	307,212,123	1,600,000,000	19%	81%		5.21
Uzbekistan	27,606,007	70,225			49,500	0.003
Venezuela	26,814,843	39,324,500	58%	42%		1.47
Viet Nam	86,967,524	759,000	100%	0%		0.009
Zimbabwe	11,392,629	219,000	19%	81%	211,000	0.02
Totals:	4,379,260,886	5,465,046,526	40%	56%	13,835,478	1.25

The quantities of Factor VIII in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2008 while others report the amount *purchased*. Where available the percentage of plasma-derived and recombinant product used is reported. The FVIII 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. Please note that some FVIII products are used in the treatment of von Willebrand disease and not for hemophilia A.

Reported Use of Factor Concentrates: Factor IX

Country	Population	D1B. Factor IX total IU	Percent plasma-derived	Percent recombinant	D4B. Humanitarian aid factor IX	FIX per cap
Albania	3,639,453	350,000			180,000	0.10
Algeria	34,178,188	401,400				0.01
Argentina	40,913,584	9,500,000	94%	6%		0.23
Armenia	2,967,004	11,000	0%	100%		0.004
Australia	21,262,641	21,322,500	13%	87%		1.00
Azerbaijan	8,238,672	600,000				0.07
Bangladesh	156,050,883	50,000	100%	0%		0.0003
Belarus	9,648,533	535,000				0.06
Belize	307,899	120,000			50,000	0.39
Bosnia-Herzegovina	4,613,414	150,000	100%	0%		0.03
Brazil	198,739,269	41,000,000	100%	0%		0.21
Bulgaria	7,204,687	300,000	100%	0%		0.04
Canada	33,487,208	37,047,714	14%	86%		1.11
Chile	16,601,707	8,400,000				0.51
Colombia	45,644,023	4,300,000	35%	65%	5,000	0.09
Costa Rica	4,253,877	4,464,000	100%	0%		1.05
Cuba	11,451,652	137,500	100%	0%		0.01
Dominican Republic	9,650,054	90,032	0%	100%	90,032	0.009
Ecuador	14,573,101	203,250	96%	4%	8,850	0.01
France	64,057,792	55,998,060	45%	55%		0.87
Georgia	4,615,807	400,000	100%	0%		0.09
Germany	82,329,758	74,500,000	90%	10%		0.90
Greece	10,737,428	5,077,310	4%	96%		0.47
Hungary	9,905,596	5,200,000	100%	0%		0.52
India	1,166,079,217	529,450	100%	0%		0.0005
Indonesia	240,271,522	11,000			11,000	0.00005
Iran	66,429,284	20,000,000				0.30
Ireland	4,203,200	10,101,750	0%	100%		2.40
Italy	58,126,212	50,000,000	40%	60%		0.86
Japan	127,078,679	35,600,000	100%	0%		0.28
Jordan	6,342,948	200,000			14,700	0.03
Kazakhstan	15,399,437	1,548,000				0.10
Korea	48,508,972	19,115,000	8%	92%		0.39
Kyrgyzstan	5,431,747	500				0.0001
Latvia	2,231,503	564,000	100%	0%		0.25
Lebanon	4,017,095	661,200	97%	3%	61,200	0.16
Lithuania	3,555,179	200,000	100%	0%		0.06
Macedonia	2,066,718	364,500	100%	0%		0.18
Malaysia	25,715,819	8,000,000	100%	0%		0.31
Mexico	111,211,789	11,163,350				0.10
Nepal	28,563,377	19,500				0.001
New Zealand	4,213,418	1,617,000	100%	0%		0.38
Oman	3,418,085	111,000	100%	0%		0.03
Pakistan	176,242,949	1,775,120	99%	1%	1,745,120	0.01
Palestine	4,013,126	113,600	100%	0%		0.03



Country	Population	D1B. Factor IX total IU	Percent plasma-derived	Percent recombinant	D4B. Humanitarian aid factor IX	FIX per cap
Panama	3,360,474	71,940	100%	0%		0.02
Peru	29,546,963	294,500	100%	0%		0.010
Philippines	97,976,603	67,646	5%	95%	67,646	0.001
Portugal	10,707,924	5,560,000	86%	14%		0.52
Russia	140,041,247	60,432,250	100%	0%		0.43
Saudi Arabia	28,686,633	1,284,000	100%	0%		0.04
Serbia	7,379,339	781,500	100%	0%		0.11
Singapore	4,657,542	450,000	100%	0%		0.10
Slovak Republic	5,463,046	2,300,000	100%	0%		0.42
Slovenia	2,005,692	646,000	100%	0%		0.32
South Africa	49,052,489	4,073,500	100%	0%		0.08
Spain	40,525,002	24,973,500	50%	50%		0.62
Sudan	41,087,825	459,000	100%	0%		0.01
Sweden	9,059,651	13,620,000	55%	45%		1.50
Switzerland	7,604,467	5,000,000	92%	8%		0.66
Syria	20,178,485	350,000				0.02
Tunisia	10,486,339	629,000	100%	0%		0.06
Turkey	76,805,524	16,034,700				0.21
United States	307,212,123	250,100,000	0%	100%		0.81
Venezuela	26,814,843	4,198,200	100%	0%		0.16
Totals:	3,820,339,099	823,608,472	41%	52%	2,233,548	0.22

The quantities of Factor IX in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2008 while others report the amount purchased. Where available the percentage of plasma-derived and recombinant product used is reported. 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.

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)		<input type="checkbox"/>
B2. Number of identified people with von Willebrand disease (vWD)		<input type="checkbox"/>
B3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		<input type="checkbox"/>

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

B4a. What is the source of the numbers provided for this survey?	<p>Check one</p> <p><input type="checkbox"/> A registry of all PWH and other inherited bleeding disorders in your country.</p> <p><input type="checkbox"/> A registry of all PWH and other inherited bleeding disorders in your country's hemophilia treatment centres.</p> <p><input type="checkbox"/> Count information provided by all of your country's hemophilia treatment centres</p> <p><input type="checkbox"/> Count information provided by some of your country's hemophilia treatment centres.</p> <p><input type="checkbox"/> Other (Describe):</p>
B4e. Is your database updated throughout the year or only once per year?	<p><input type="checkbox"/> Ongoing update (can be updated anytime)</p> <p><input type="checkbox"/> Yearly update (the registry is updated once each year)</p> <p><input type="checkbox"/> Other (please describe):</p>
B4f. Who updates the database?	<p><input type="checkbox"/> Doctors update the database</p> <p><input type="checkbox"/> Patient organization updates the database</p> <p><input type="checkbox"/> Hospitals or clinics update the database</p> <p><input type="checkbox"/> Other (please describe):</p>



Age distribution of people with Hemophilia and von Willebrand disease

Age group	Number with hemophilia A	Number with hemophilia B	Number with VWD
B6. 0 - 13 years old			
B7. 14 - 18 years old			
B8. 19 years old and over			
B9. No age data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Type of hereditary bleeding disorder

Diagnosis	Total	Male	Female	No data
B10. Hemophilia A				<input type="checkbox"/>
B11. Hemophilia B				<input type="checkbox"/>
B12. Hemophilia, type unknown				<input type="checkbox"/>
B13. von Willebrand disease				<input type="checkbox"/>
B14a. Other hereditary bleeding disorders: Factor I deficiency				<input type="checkbox"/>
B14b. Other hereditary bleeding disorders: Factor II deficiency				<input type="checkbox"/>
B14c. Other hereditary bleeding disorders: Factor V deficiency				<input type="checkbox"/>
B14d. Other hereditary bleeding disorders: Factor V+VIII deficiency				<input type="checkbox"/>
B14e. Other hereditary bleeding disorders: Factor VII deficiency				<input type="checkbox"/>
B14f. Other hereditary bleeding disorders: Factor X deficiency				<input type="checkbox"/>
B14g. Other hereditary bleeding disorders: Factor XI deficiency				<input type="checkbox"/>
B14h. Other hereditary bleeding disorders: Factor XIII deficiency				<input type="checkbox"/>
B14j. Other hereditary bleeding disorders: type unknown				<input type="checkbox"/>
B14i.1 Platelet disorders: Glanzmann's thrombasthenia				<input type="checkbox"/>
B14i.2 Platelet disorders: Bernard Soulier Syndrome				<input type="checkbox"/>
B14i.3 Platelet disorders: other or unknown				<input type="checkbox"/>

B14k. How are patients with rare bleeding disorders identified?

Factor level below 5% <input type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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Number of identified people with hemophilia by diagnosis of severity

Type of hemophilia	Mild	Moderate	Severe	No Data
B15a. Hemophilia A				<input type="checkbox"/>
B16a. Hemophilia B				<input type="checkbox"/>

Number of severe VWD patients

B13b. Total number of severe VWD patients	B13c. Number of VWD patients receiving replacement therapy	B13d. Number of VWD patients with severe bleeding symptoms	No Data
			<input type="checkbox"/>

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		<input type="checkbox"/>
B16b. Hemophilia B		<input type="checkbox"/>

HIV and hepatitis C testing among living people with hemophilia

Infectious Disease	Number of people infected	Number of people tested	No Data
B26. HIV			<input type="checkbox"/>
B27. Hepatitis C			<input type="checkbox"/>

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

Infectious Disease	Number of people infected	Number of people tested	No Data
B28. HIV			<input type="checkbox"/>
B29. Hepatitis C			<input type="checkbox"/>

Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2008)

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:	
C3. How are the majority of people with hemophilia diagnosed? (check one only)	<input type="checkbox"/> Clinical symptoms only
	<input type="checkbox"/> Clotting screening tests only (e.g. PT or APTT)
	<input type="checkbox"/> Specific factor assays for factor VIII or IX
	<input type="checkbox"/> Not known
C4. Who pays for the medical care for the majority of people with hemophilia? (check one only)	<input type="checkbox"/> Government (social security, public health care system, etc.)
	<input type="checkbox"/> Private insurance
	<input type="checkbox"/> Patient
C5. Who pays for the medicine for the majority of people with hemophilia? (check one only)	<input type="checkbox"/> Government (social security, public health care system etc.)
	<input type="checkbox"/> Private insurance
	<input type="checkbox"/> Patient



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 2008?			<input type="checkbox"/>
D2. How many international units of plasma-derived concentrates were used in your country in 2008?			<input type="checkbox"/>
D3. How many international units of recombinant concentrates were used in your country in 2008?			<input type="checkbox"/>
D4. How many international units were humanitarian aid ?			<input type="checkbox"/>

Suggestions for next year's survey:

Completed by:

Date:

Contact info:

Please return to: Mark Brooker, WFH Senior Public Policy Officer

Email: mbrooker@wfh.org

Fax: (514-875-8916)

or return by mail to:

World Federation of Hemophilia
1425 René Lévesque Boulevard West, suite 1010,
Montréal, Québec, H3G 1T7, Canada

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 lib/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.

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

VWD: von Willebrand disease.





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