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# World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2009

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All data are provisional.

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## Table of Contents

Introduction.....	1
Summary of survey data.....	3
Graphs – number of identified patients.....	4
Graphs – per capita factor usage.....	7
Countries included in the survey.....	11
Population statistics .....	12
Distribution of reported bleeding disorders by country .....	15
Gender breakdowns .....	18
Patients with inhibitors .....	19
Age breakdowns Hemophilia and VWD.....	21
HIV and HCV infection .....	26
Healthcare system.....	28
Reported use of factor concentrates.....	29
Annual Global Survey 2009 sample questionnaire.....	33
Glossary.....	40



## Introduction to the Report on the WFH Global Survey 2009

Report on the Annual Global Survey 2009 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 2009 survey is the eleventh WFH survey. This report uses data for the years 2005, 2006, 2007, 2008 and 2009. 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 11. The survey includes data on more than 240,000 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.

### 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 4 to 10 use data from the 2009, 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 2009 or 2008. 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. In the extremely rare bleeding disorders, consanguinity may lead to an increased incidence in some countries.
- b) Countries with small populations can appear to have too many identified patients. Countries submitting data to the WFH range in population from 300,000 to over a billion. With a small denominator (total population), just a few extra identified patients (the numerator) can create the appearance of huge percentage differences between expected and identified patients when really there are only a few more patients than expected.
- c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they don't require treatment. In countries with different health care systems, it is likely that patients 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. In the case of the rare bleeding disorders, some countries may report heterozygous patients while other countries report only patients with bleeding symptoms.
- e) Some countries are reporting every patient 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.



## **2009 WFH Global Survey Summary**

### **Demographics**

Number of countries in this survey: **105**  
Percentage of world population covered by 2009 survey report: **92%**

Number of people identified with hemophilia A and B: **153,251**  
Number of people identified with VWD: **62,158**  
Number of people identified with other bleeding disorders: **27,030**

Total number of people with bleeding disorders identified: **242,517**

Number of people with hemophilia A: **115,204**  
Number of people with hemophilia B: **24,038**

Number of hemophilia A patients with clinically identified inhibitors: **5013**  
Number of hemophilia B patients with clinically identified inhibitors: **363**

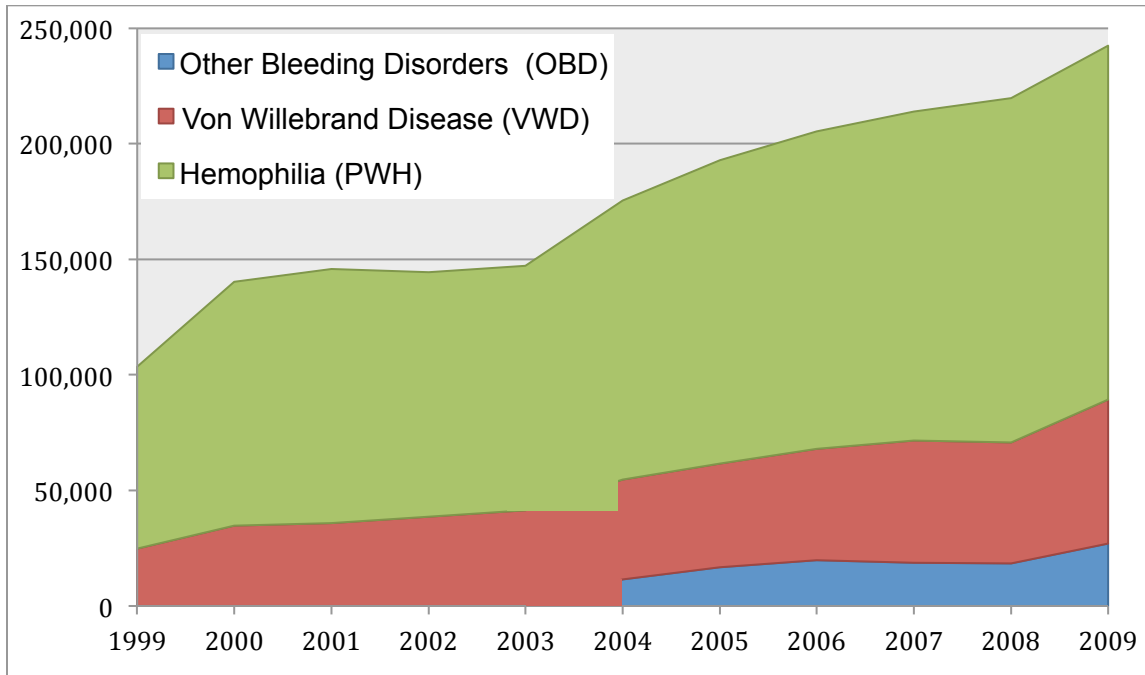
Reported number of PWH infected with HIV: **5,665**  
Reported number of PWH infected with HCV: **24,340**  
Reported number of patients with VWD infected with HIV: **119**  
Reported number of patients with VWD infected with HCV: **1,513**

### **Factor usage**

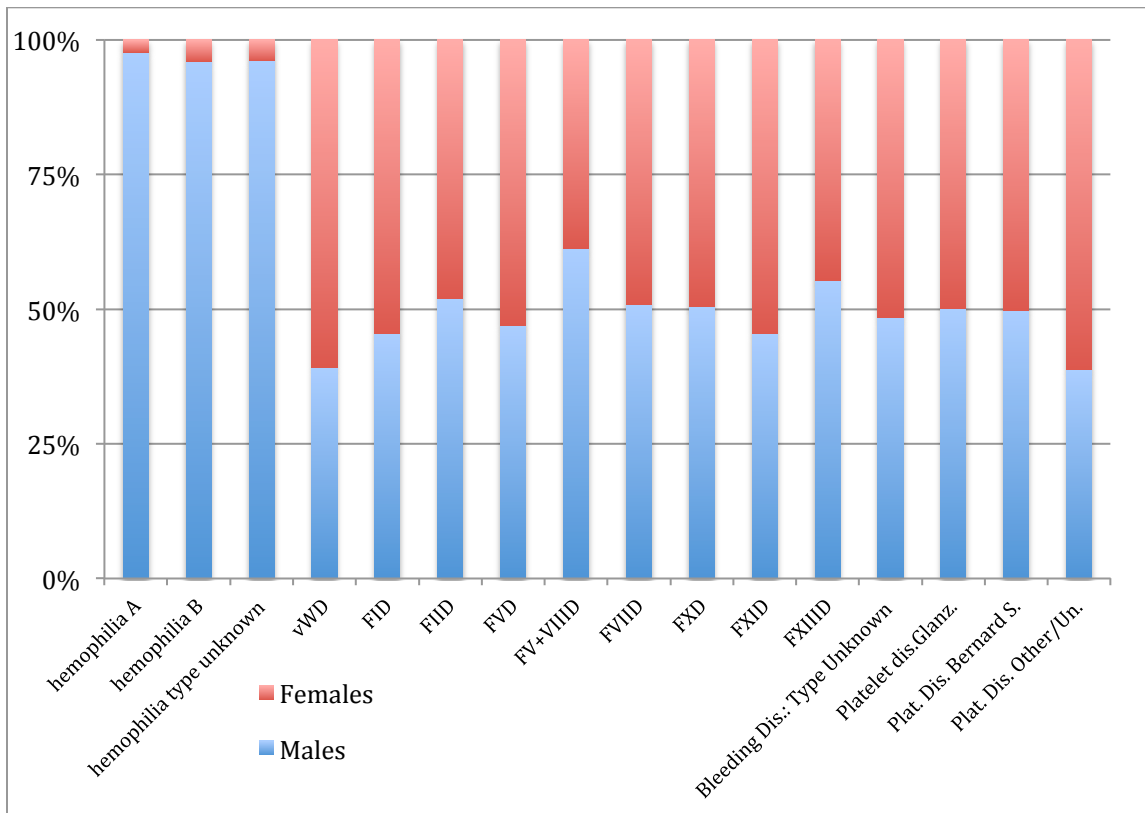
Mean global per capita factor VIII usage: **2.02 IU** (*86 countries reporting*)  
Mean global per capita factor IX usage: **0.28 IU** (*74 countries*)

Total reported annual global consumption of factor VIII concentrates: **7,333,984,513 IU**  
Total reported annual global consumption of factor IX concentrates: **956,767,192 IU**

A. Identified patients – all disorders (collection of data on rare bleeding disorders began in 2004)

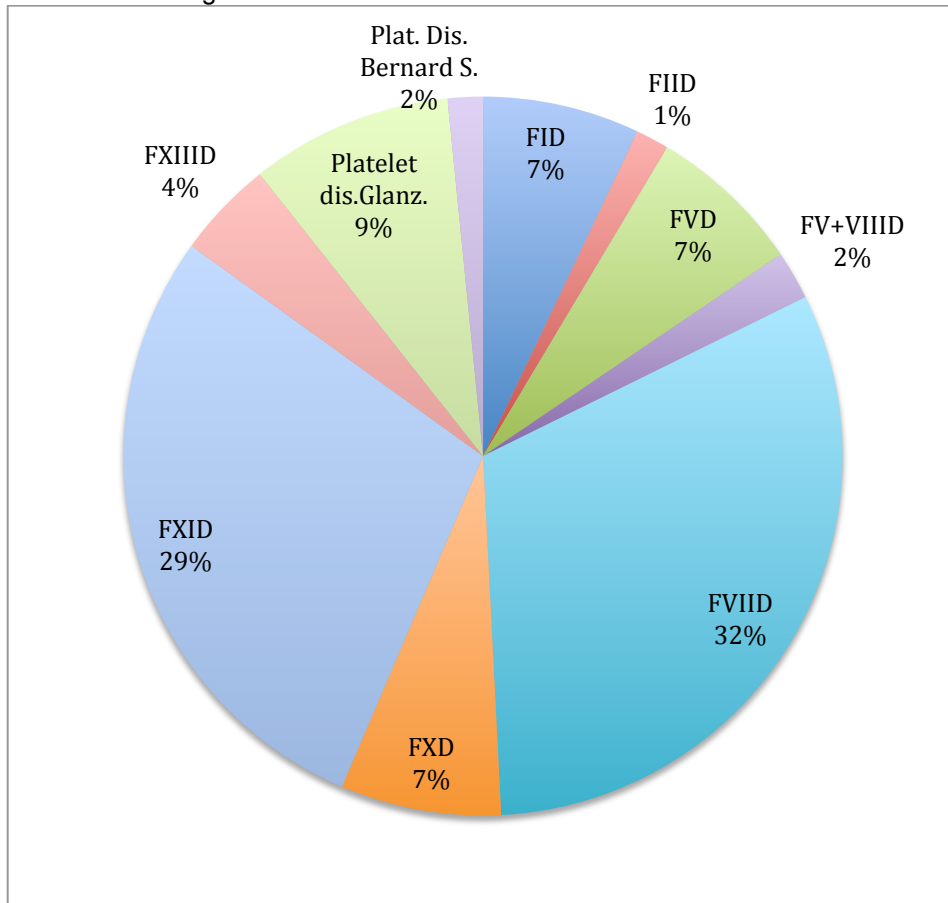


B. The graph below shows the proportion of male and female patients for the all bleeding disorders. (See gender data on page 18.) These data are from the 72 countries that provided gender breakdowns.

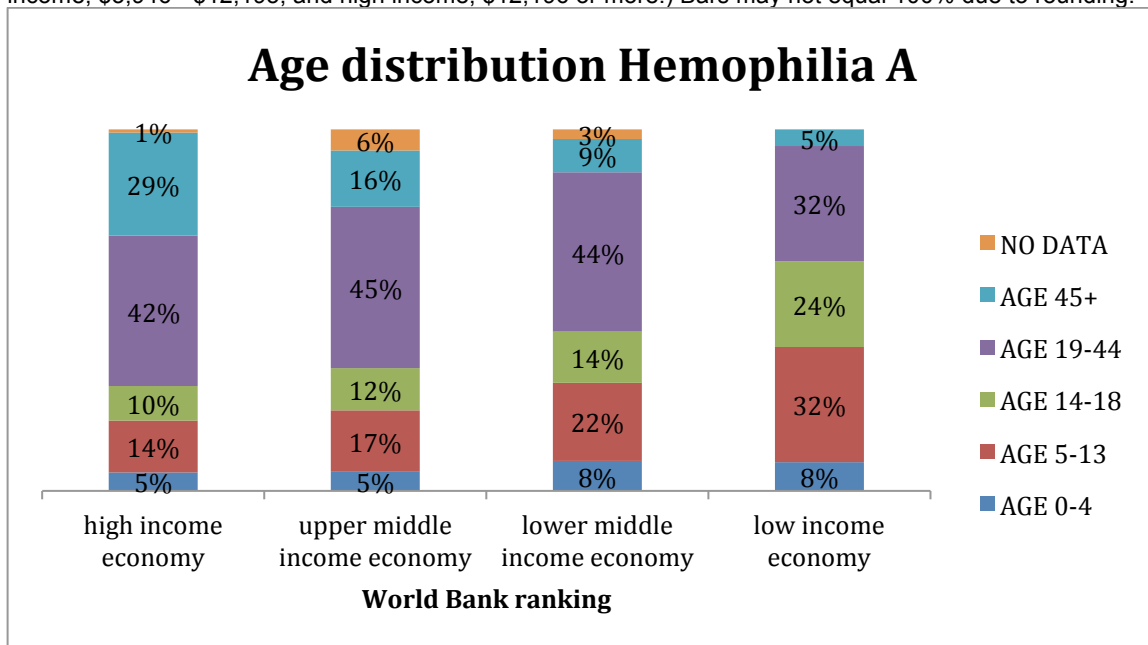


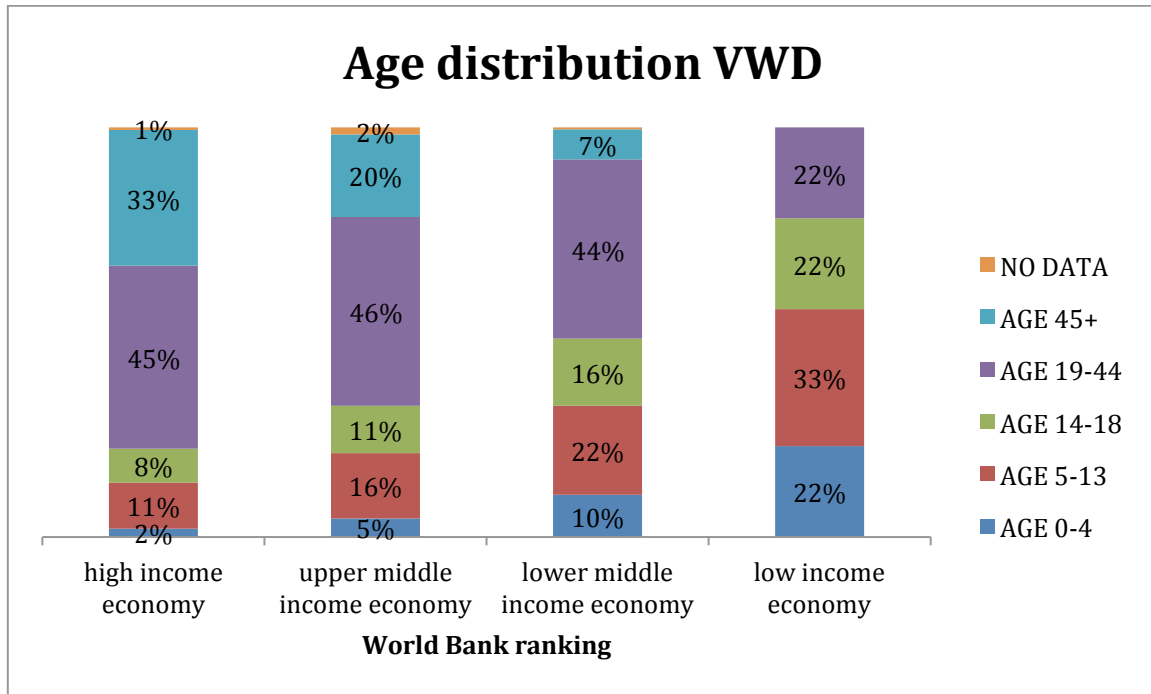
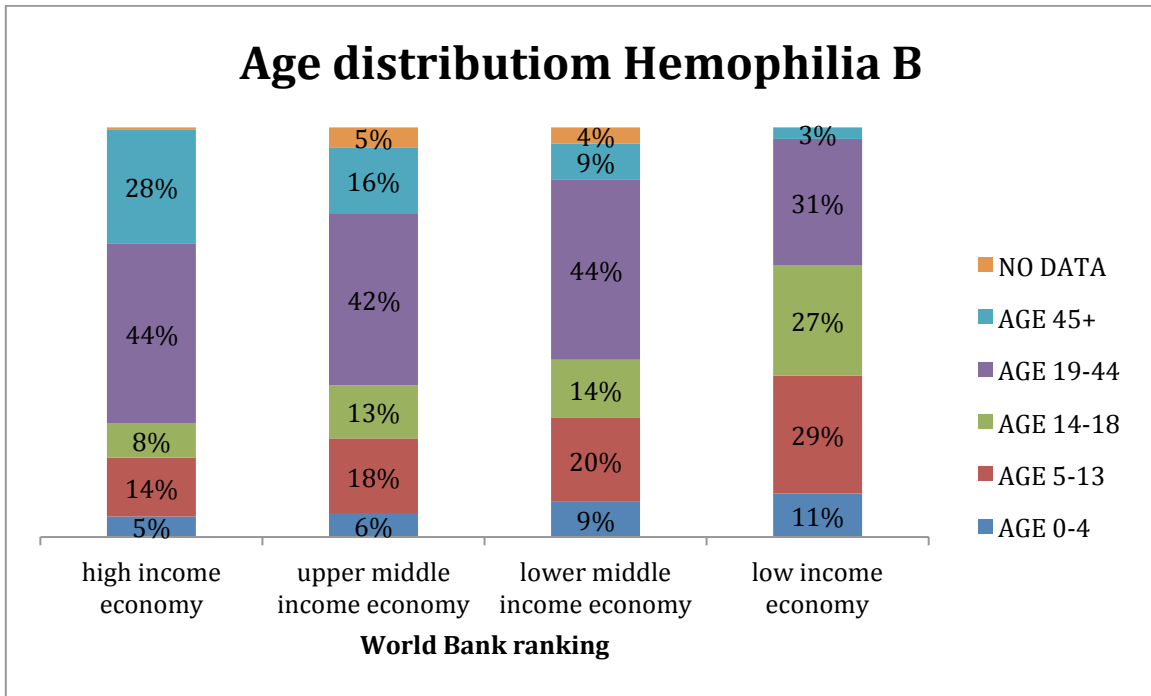


C. Distribution of rare bleeding disorders

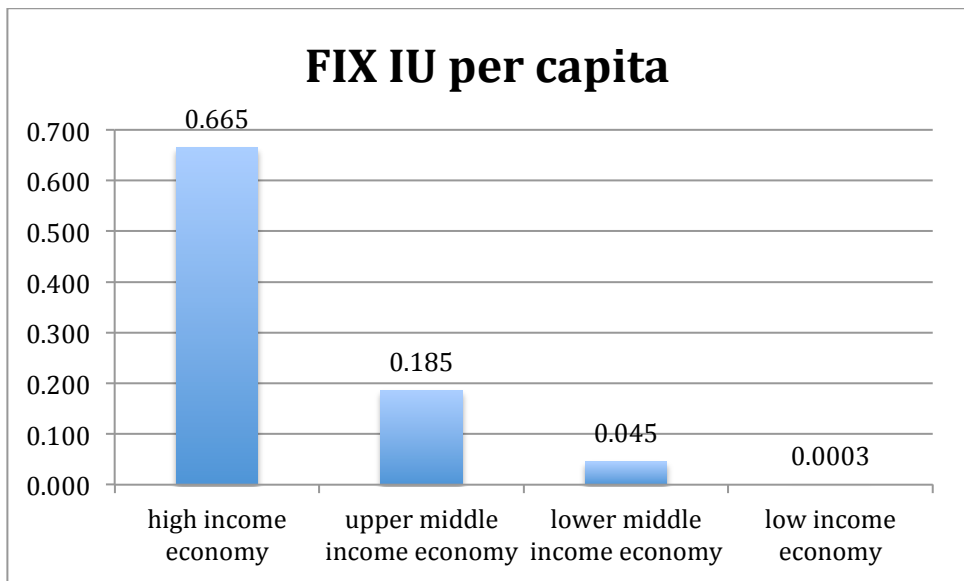
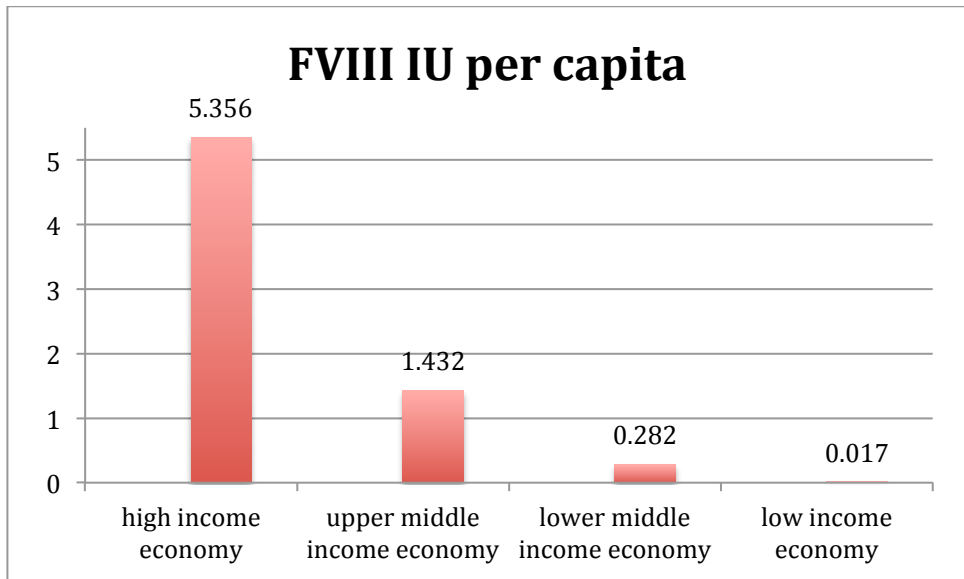


D. Age distribution according to economic ranking. Categories are based on the World Bank rankings for 2009. (GNI in US dollars: low income, \$995 or less; lower middle income, \$996 - \$3,945; upper middle income, \$3,946 - \$12,195; and high income, \$12,196 or more.) Bars may not equal 100% due to rounding.

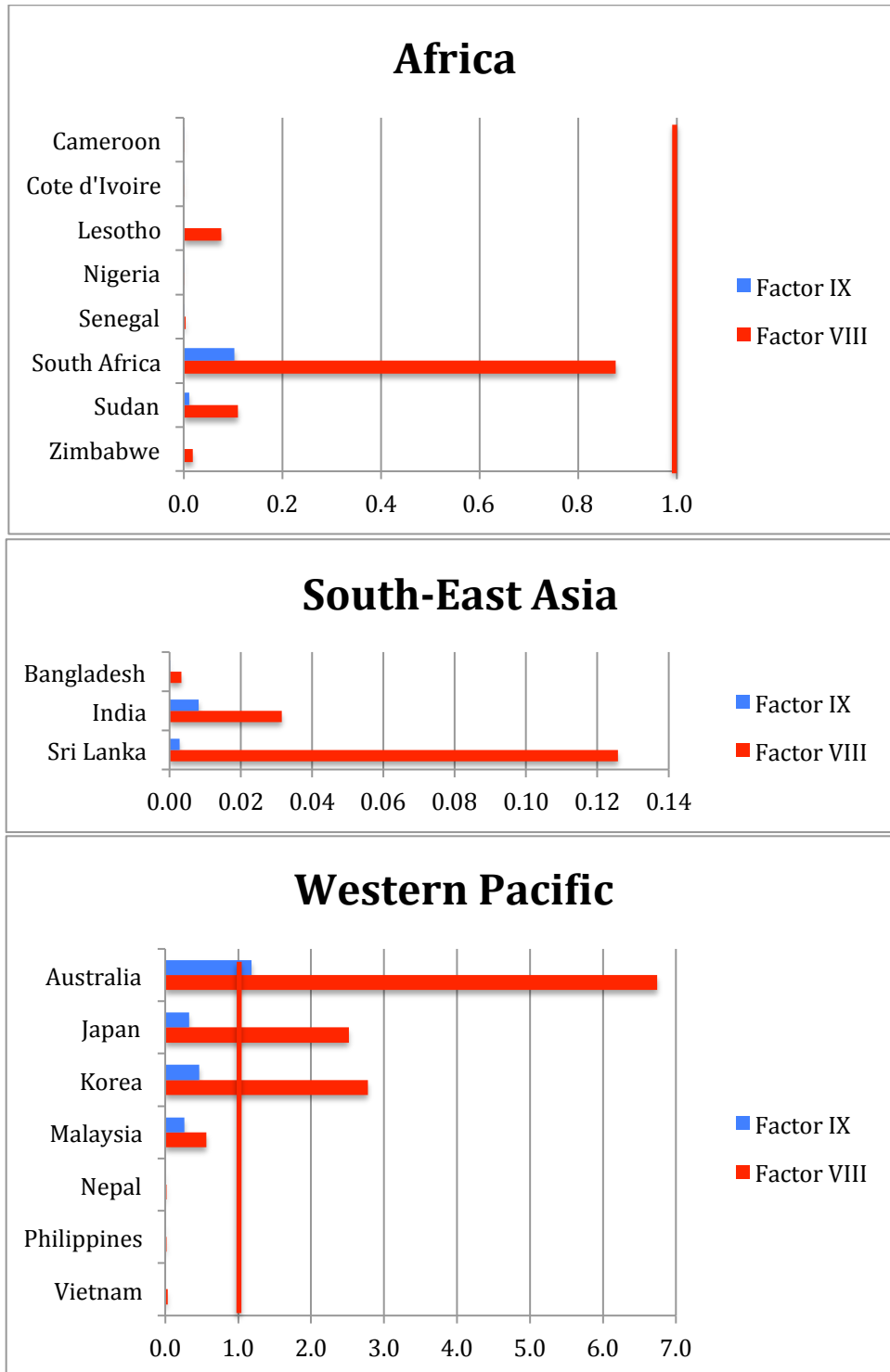




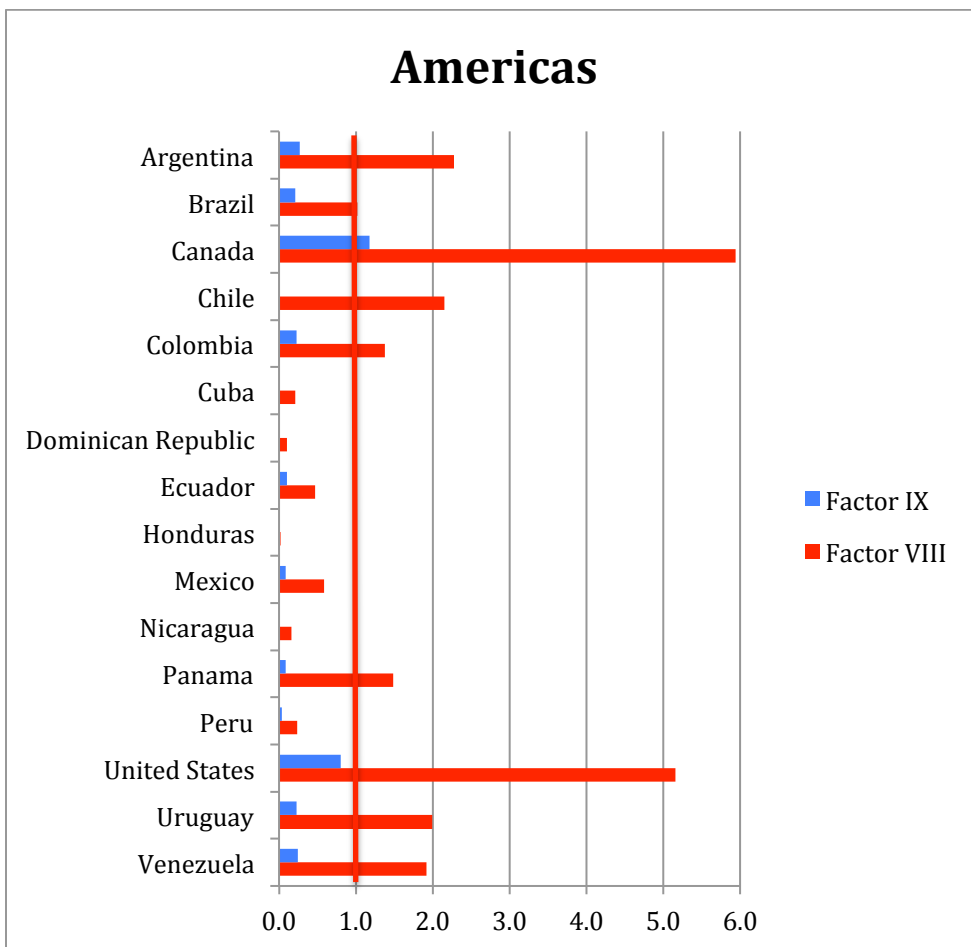
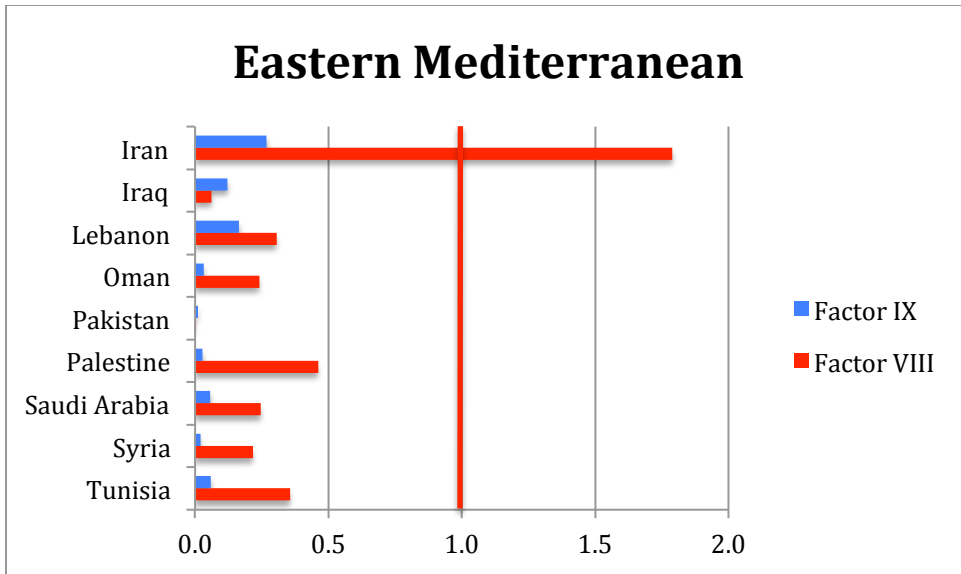
E. Global factor use based on World Bank rankings. Categories are based on the rankings for 2009. (GNI in US dollars: low income, \$995 or less; lower middle income, \$996 - \$3,945; upper middle income, \$3,946 - \$12,195; and high income, \$12,196 or more.)



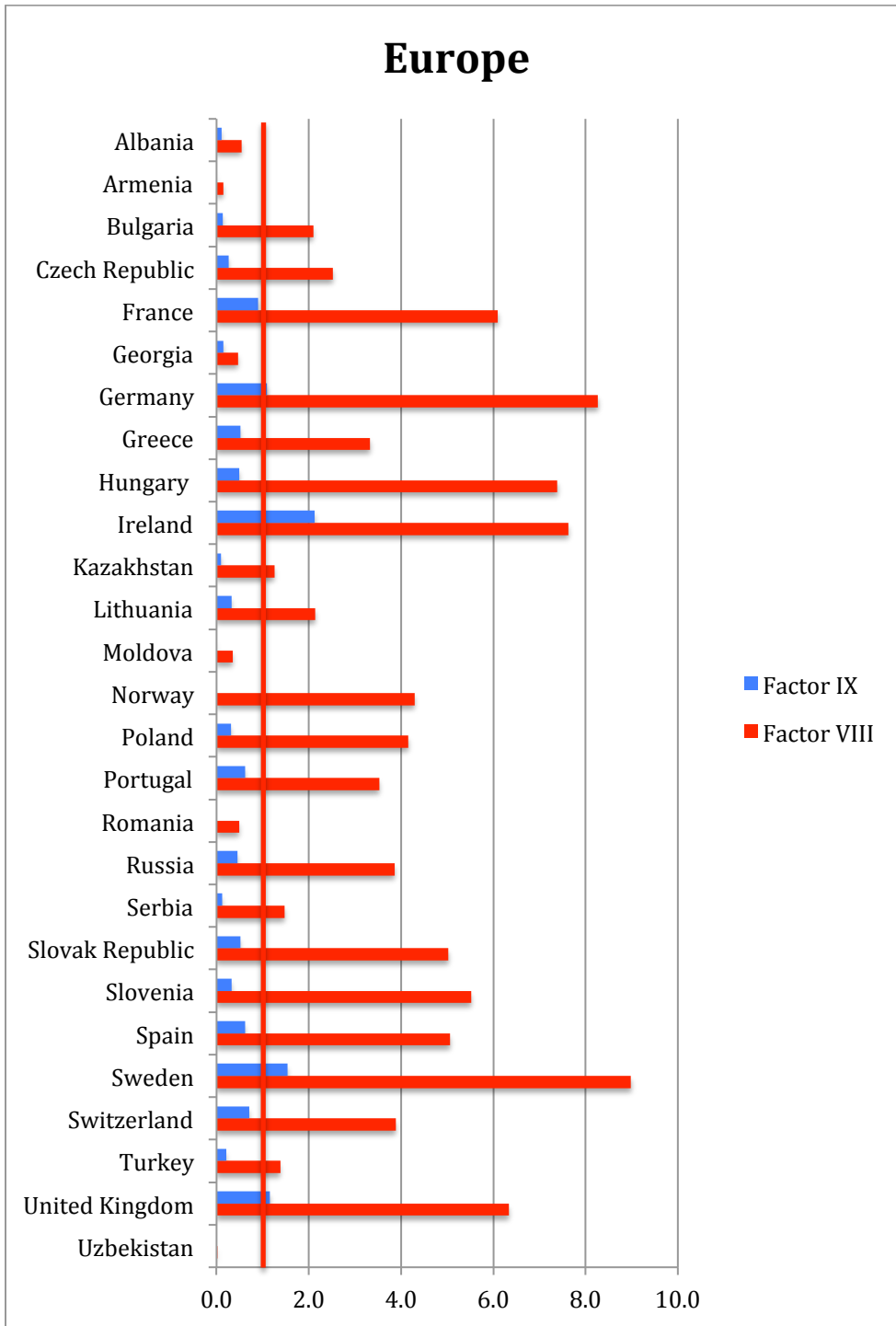
F. Per capita factor use – regional comparisons of IU/total population.



PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the red line does not apply to factor IX.



PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the red line does not apply to factor IX.



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## Countries included in the 2009 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 2009 Survey report, 79 countries submitted data for 2009. The data used from other years is as follows. 2008: 11 countries, 2007: 10 countries, 2006: 5 countries, 2005: 1 country.)

1. Albania	2009	37. Guatemala	2009	74. Paraguay	2009
2. Algeria	2007	38. Honduras	2009	75. Peru	2009
3. Argentina	2009	39. Hungary	2009	76. Philippines	2009
4. Armenia	2009	40. Iceland	2007	77. Poland	2009
5. Australia	2009	41. India	2009	78. Portugal	2009
6. Austria	2009	42. Indonesia	2009	79. Qatar	2006
7. Azerbaijan	2007	43. Iran	2009	80. Romania	2009
8. Bahrain	2007	44. Iraq	2009	81. Russia	2009
9. Bangladesh	2009	45. Ireland	2009	82. Saudi Arabia	2009
10. Belarus	2009	46. Israel	2009	83. Senegal	2009
11. Belgium	2009	47. Italy	2007	84. Serbia	2009
12. Belize	2009	48. Japan	2009	85. Singapore	2006
13. Bosnia- Herzegovina	2006	49. Jordan	2006	86. Slovak Republic	2009
14. Brazil	2009	50. Kazakhstan	2008	87. Slovenia	2009
15. Bulgaria	2009	51. Kenya	2007	88. South Africa	2009
16. Cambodia	2009	52. Korea, Republic of	2009	89. Spain	2009
17. Cameroon	2009	53. Kuwait	2005	90. Sri Lanka	2009
18. Canada	2009	54. Kyrgyzstan	2007	91. Sudan	2009
19. Chile	2009	55. Latvia	2009	92. Sweden	2009
20. China	2009	56. Lebanon	2008	93. Switzerland	2009
21. Colombia	2009	57. Lesotho	2009	94. Syria	2009
22. Costa Rica	2009	58. Lithuania	2009	95. Thailand	2009
23. Cote d'Ivoire	2009	59. Macedonia	2006	96. Tunisia	2008
24. Croatia	2007	60. Malaysia	2009	97. Turkey	2009
25. Cuba	2009	61. Mexico	2009	98. Ukraine	2007
26. Czech Republic	2009	62. Moldova	2009	99. United Kingdom	2009
27. Denmark	2009	63. Mongolia	2007	100. United States	2009
28. Dominican Republic	2009	64. Nepal	2009	101. Uruguay	2009
29. Ecuador	2009	65. Netherlands	2009	102. Uzbekistan	2009
30. Egypt	2009	66. New Zealand	2009	103. Venezuela	2009
31. Eritrea	2008	67. Nicaragua	2009	104. Vietnam	2009
32. Finland	2009	68. Nigeria	2009	105. Zimbabwe	2008
33. France	2009	69. Norway	2008		
34. Georgia	2009	70. Oman	2008		
35. Germany	2009	71. Pakistan	2009		
36. Greece	2009	72. Palestine	2008		
		73. Panama	2008		

### 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 *	Number of PWH	Number of people with vWD	Number of people with OBD†
Albania	3,659,616	268		
Algeria	34,178,188	1,291	109	
Argentina	41,343,201	2,104	354	
Armenia	2,966,802	208	10	10
Australia	21,515,754	2,283	1,904	1,652
Austria	8,214,160	509		
Azerbaijan	8,238,672	846	218	40
Bahrain	727,785	20		4
Bangladesh	158,065,841	424	0	6
Belarus	9,612,632	546	171	45
Belgium	10,423,493	936	1,193	390
Belize	314,522	14		
Bosnia-Herzegovina	4,613,414	140	30	
Brazil	201,103,330	10,026	3,880	982
Bulgaria	7,148,785	589	79	38
Cambodia	14,753,320	63	1	2
Cameroon	19,294,149	68	1	0
Canada	33,759,742	3,256	3,439	1,321
Chile	16,746,491	1,252		
China	1,330,141,295	4,195		
Colombia	43,677,372	1,920	208	154
Costa Rica	4,516,220	188	63	22
Cote d'Ivoire	21,058,798	48	2	3
Croatia	4,489,409	477	282	139
Cuba	11,477,459	395	65	1,490
Czech Republic	10,211,904	833		
Denmark	5,515,575	475	405	85
Dominican Republic	9,794,487	245	103	32
Ecuador	14,790,608	238	45	13
Egypt	80,471,869	5,307	455	986
Eritrea	5,647,168	46		
Finland	5,255,068	322	2,943	40
France	64,057,792	5,153	1,017	320
Georgia	4,600,825	276	19	8
Germany	82,282,988	4,230	4,674	

\* Population data source: CIA World Factbook, 2009

† OBD: Other bleeding disorders (Rare factor deficiencies and platelet disorders.)



Country	Population*	Number of PWH	Number of people with vWD	Number of people with OBD†
Greece	10,749,943	890	684	215
Guatemala	13,550,440	106	16	72
Honduras	7,989,415	209	6	5
Hungary	9,905,596	1,001	1,305	422
Iceland	306,694	64	96	
India	1,173,108,018	13,453	290	504
Indonesia	242,968,342	1,242	1	
Iran	67,037,517	4,939	942	1,636
Iraq	28,945,569	841	168	181
Ireland	4,203,200	669	939	664
Israel	7,353,985	520	2	
Italy	58,126,212	3,270	1,650	700
Japan	126,804,433	5,250	917	474
Jordan	6,342,948	248		45
Kazakhstan	15,399,437	1,360	460	108
Kenya	39,002,772	461	22	
Korea, Republic of	48,636,068	1,844	86	59
Kuwait	2,691,158			
Kyrgyzstan	5,431,747	206		
Latvia	2,217,969	139	102	2
Lebanon	4,017,095	165	63	37
Lesotho	2,130,819	15	1	0
Lithuania	3,545,319	152	149	43
Macedonia	2,066,718	280	40	
Malaysia	26,160,256	1,141	440	337
Mexico	112,468,855	4,178	164	2
Moldova	4,317,483	235	3	
Mongolia	3,041,142	49	2	4
Nepal	28,951,852	298		9
Netherlands	16,783,092	1,397	257	65
New Zealand	4,252,277	384	159	19
Nicaragua	5,995,928	217	59	4
Nigeria	152,217,341	126	6	
Norway	4,660,539	397	858	37
Oman	3,418,085	93	262	296
Pakistan	176,242,949	268	182	187
Palestine	4,013,126	131	7	56
Panama	3,410,676	262	346	16
Paraguay	6,375,830	448	1	1
Peru	29,907,003	549	72	14
Philippines	99,900,177	1,026	29	

Country	Population*	Number of PWH	Number of people with vWD	Number of people with OBD†
Poland	38,463,689	2,580	1,147	632
Portugal	10,735,765	614	51	14
Qatar	833,285	112	7	62
Romania	22,181,287	1,649	348	15
Russia	139,390,205	5,739	1,250	930
Saudi Arabia	29,207,277	326	75	36
Senegal	14,086,103	123	8	4
Serbia	7,344,847	423	226	16
Singapore	4,657,542	204	58	85
Slovak Republic	5,470,306	557	472	820
Slovenia	2,003,136	196	147	92
South Africa	49,109,107	1,817	527	209
Spain	40,548,753	1,985	710	210
Sri Lanka	21,513,990	526		
Sudan	41,087,825	618	54	52
Sweden	9,074,055	1,020	1,538	
Switzerland	7,623,438	672	126	66
Syria	22,198,110	300	30	16
Thailand	66,404,688	1,029	65	49
Tunisia	10,486,339	250	76	112
Turkey	77,804,122	3,852	362	782
Ukraine	45,700,395	2,600		
United Kingdom	61,284,806	6,460	8,773	6,308
United States	310,232,863	16,667	12,524	1,607
Uruguay	3,510,386	236	316	11
Uzbekistan	27,865,738	1,155	88	33
Venezuela	27,223,228	1,999	701	663
Vietnam	89,571,130	1,595	30	210
Zimbabwe	11,392,629	311	3	
<b>TOTALS</b>	<b>6,056,321,803</b>	<b>153,329</b>	<b>62,158</b>	<b>27,030</b>

### Distribution of reported bleeding disorders by country

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

Country	Hemophilia A Total	Hemophilia B Total	Hemophilia type unknown Total	vWD Total	FID Total	FIIID Total	FVD Total	FV+VIIID Total	FVIIID Total	FXD Total	FXID Total	FXIIID Total	Bleeding Dis.: Type Unknown Total	Platelet dis. Glanz. Total	Plat. Dis. Bernard S. Total	Plat. Dis. Other/Unknown
Algeria (2007)	962	200	120													
Argentina	1,842	262	159	354												16
Armenia	184	18		10	5			2	2	1				1		
Australia	1,835	448		1,904			8	47	10	105	16	1,319	5	1	141	
Austria																
Azerbaijan (2007)	810	36	32	218		3			3	1			6		1	4
Bahrain (2007)	19	1							1	3				2	1	
Bangladesh (2008)	367	57	5									1				
Belarus	452	94		171					14	1	26	4				
Belgium	874	196		1,193			16		46	4	72	2	10	17		
Belize	9	5														
Bosnia-Herzegovina (2006)	100	10		30												
Brazil	8,436	1,590		3,880	23	5	61	3	233	47	69	21	286	90	1	79
Bulgaria	531	58		79	7	1	1		6	3	2	2	83	10		9
Cambodia	55	8		1								1		1		2
Cameroon	78	4	8													
Canada	2,625	631		3,439	102	9	51	4	225	30	302	49	2	54	26	497
Chile	1,068	184														
Colombia	1,431	311	144	208	21	9	9	2	17	1	8	7	15	5	2	30
Cote d'Ivoire	32	8		2	0	0	0	0	0	2	1	0	0	0	0	0
Croatia (2007)	385	92	0	282	6	0	12	3	48	3	19	7	3			17
Cuba	395	67		65	1	1	1	1	0	0	8	4	0	2	0	1,488
Czech Republic	715	112	6													
Denmark	382	93	0	405	1	1	2		4	8	4	8		9	10	38
Dominican Republic	216	29		88										2		
Ecuador	437	50		79	1		1		2	1	3	1	5			
Egypt	129	37		25	8	1	4	1	4	12	1	4		20		
Eritrea (2008)	41	5														
Finland	250	72	0	2,943	12	2	5	0	7	0	1	13		0	>20	
France	4,223	930	0	1,017	34	1	31	9	97	17	106	25				
Georgia	206	40		19					2			1		5		
Germany	3,629	601		4,674												
Greece	750	140		684	16	1	6		56	7	46	10	1	13	7	52
Guatemala	98	8		16												
Honduras	195	14	48	6					1		1	2				
Hungary	803	198		1,305	13	1	13		192	15	60	1		8	2	17
Iceland (2007)	63	2	0	96										0	12	
India	11,388	2,065		290												
Indonesia	286	42	914	5												
Iran	4,063	876		942	94	17	103	152	293	120	85	37		334	29	335
Iraq	633	208		168	31		1		45	11	1	13				79

Country	Hemophilia A Total	Hemophilia B Total	Hemophilia type unknown Total	vWD Total	FID Total	FIIID Total	FVD Total	FV+VIIID Total	FVIIID Total	FXD Total	FXIID Total	FXIIID Total	Bleeding Dis.: Type Unknown Total	Platelet dis.Glanz. Total	Plat. Dis. Bernard S. Total	Plat. Dis. Other/Unknown
Ireland	451	218		939			51		61	70	93	4	363	9	3	10
Israel	428	92														
Italy (2007)	2,697	573	21	1,650	49	14	73	23	308	54	156	21	45			115
Japan	4,317	933		917	58	6	23	6	53	15	26	57		12	2	
Jordan (2006)	202	46					1		51	3	3	6				
Kazakhstan (2008)	1,036	324		460												
Korea, Republic of	1,507	337	20	86	4	0	2		20		13	4				
Kyrgyzstan (2007)	197	9												1		
Latvia	115	24		102					2							
Lebanon (2008)	109	29		62	21	1	4	1	1	1	3	2				3
Lesotho	15	0	0	1	0											
Lithuania	130	22	0	149	0	0	2	0	35	0	1	3				11
Macedonia (2006)	200	80		40												
Malaysia	968	173		330	4	2	18	0	42	13	38	13		41	0	34
Mexico	3,495	569	347	177			2		5	1				1		
Moldova	224	11		3												
Mongolia (2007)	49	4		2												
Nepal	266	32				1			1	7						
Netherlands	1,195	202														
New Zealand	312	72		159					1	1	4		11			2
Nicaragua	191	28		57	4											1
Nigeria	119	6	1	6												
Norway (2008)	301	96	0		3		2	0	23	0	0					
Oman (2008)	86	7		262	5	1	3	5	47	3	13	1	61	23	2	132
Pakistan	1,141	203	14	268	7	1	15	6	21	22	2	17	9	49	11	8
Palestine (2008)	104	27		7	11	0	2	0	0	6	0	0		36	1	
Panama (2008)	237	25		346		1			3	10					1	1
Paraguay	434	14		1					1							
Peru	481	481		118		1	3		7	2	2	1		4		10
Philippines	889	137	42	29												
Poland	2,187	375		1,147	48	0	20	3	188	15	31	9		17	2	34
Portugal	506	151		51	2		3			1	7	1	43	1		6
Qatar (2006)	87	25		7	2		6	1	6	2	20	1				
Romania	1,449	200	15	348		1		2	5		1					
Russia	5,063	676		1,205									930			
Saudi Arabia	260	66	0	75	0	2	3	1	6	1	9	13	0	66	2	0
Serbia	361	62		235	1			1	5		4	4			1	
Singapore (2006)	176	28	0	58	0	0	15	0	9	0	46	3				
Slovak Republic	485	72	0	472	59	0	42	2	537	16	34	3	0	10	6	17
Slovenia	175	21		147			9	2	10		11	1		2		
South Africa	1,532	285	0	527	7	0	43	4	18	10	27	6		15	23	48
Spain	1,712	273		710	18	3	12	3	21	9	25	18	61	12		28
Sri Lanka	413	113	28													
Sudan	514	104	0	54	8	0	11	0	4	6	0	6	10	16	3	0
Switzerland	560	112	126	10				4	26	4	8	14				
Syria	252	48		30	5		2	3	2	1				3		

Country	Hemophilia A Total	Hemophilia B Total	Hemophilia type unknown Total	vWD Total	FID Total	FIIID Total	FVD Total	FV+VIIID Total	FVIIID Total	FXD Total	FXID Total	FXIIID Total	Bleeding Dis.: Type Unknown Total	Platelet dis. Glanz. Total	Plat. Dis. Bernard S. Total	Plat. Dis. Other/Unknown
Thailand	917	112		65	1	0	2	1	12	1	0	0	0	36		
Tunisia (2008)	162	38	0	76	11	0	3	5	15	1	4	13		138	6	
Turkey	3,176	676		362		4	10	10	240	78	12	7	12	47	3	47
United Kingdom	5,330	1,128		8,773	171	9	126	23	622	175	1,799	54		103	56	1,188
United States	12,667	4,000		12,524	92	44	128		617	109	513	104				
Uruguay	185	30	21	316	1		2		3	1	2		2	1	1	
Uzbekistan	1,032	117		88		7			3				33	5	1	
Venezuela	1,567	432	0	701	42	61	29	25	115	88	245	13		13	10	22
Vietnam	1,304	291		30	1	2	3	6	7	8	2	0		59		122
TOTALS	115,204	24,038	2,071	58,780	1010	213	995	312	4500	1032	4075	628	3310	1298	226	4643

### Gender breakdowns (77 countries reporting)

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

Disorder	Male	Female
Hemophilia A	80,266	1885
Hemophilia B	17,164	708
Hemophilia type unknown	801	32
Von Willebrand Disorder	17,695	27,416
Factor I Deficiency	386	463
Factor II Deficiency	64	59
Factor V Deficiency	373	421
Factor V+VIII Deficiency	148	94
Factor VII Deficiency	1,787	1,731
Factor X Deficiency	420	412
Factor XI Deficiency	1,541	1,848
Factor XIII Deficiency	301	243
Bleeding Disorder: Type Unknown	913	973
Platelet disorders: Glanzmann's thrombasthenia	476	475
Platelet disorders: Bernard Soulier Syndrome	226	98
Platelet disorders: other or unknown	1,566	2,473

**Patients with clinically identified inhibitors** (Patients who do not respond to standard treatment.)

Country	Hemophilia A Total	Hemophilia A w/ clinically identified inhibitors	Hemophilia B Total	Hemophilia B w/ clinically identified inhibitors
Argentina	1,842	227	262	8
Armenia	184	7	18	1
Australia	1,835	58	448	4
Azerbaijan	810	4	36	
Belarus	452	42	94	39
Brazil	8,436	792	1,590	41
Bulgaria	531	16	58	1
Cambodia	55	0	8	0
Cameroon	78	0	4	0
Canada	2,625	80	631	4
Chile	1,068	31	184	1
Colombia	1,431	51	311	6
Cote d'Ivoire	32	8	8	1
Czech Republic	715	16	112	1
Denmark	382	9	93	1
Finland	250	0	72	1
France	4,223	122	930	4
Georgia	206	2	40	0
Germany	3,629	71	601	13
Greece	750	20	140	2
Guatemala	98	2	8	
Honduras	195	1	14	
Hungary	803	36	198	1
Iceland	63	0	2	0
Indonesia	286	52	42	
Iran	4,063	229	876	6
Iraq	633	12	208	1
Ireland	451	11	218	1
Israel	428	35	92	2
Italy	2,697	288	573	8
Japan	4,317	86	933	18
Jordan	202	18	46	0
Kazakhstan	1,036	5	324	2
Korea, Republic of	1,507	115	337	10
Latvia	115	2	24	2
Lebanon	109	3	29	0
Lesotho	15	0	0	0
Lithuania	130	8	22	0
Macedonia	200	3	80	1
Malaysia	968	85	173	2
Mexico	3,495	133	569	8
New Zealand	312	27	72	0
Nicaragua	191	1	28	
Norway	301	12	96	0
Oman	86	8	7	0
Pakistan	1,141	42	203	4

<b>Country</b>	<b>Hemophilia A Total</b>	<b>Hemophilia A w/ clinically identified inhibitors</b>	<b>Hemophilia B Total</b>	<b>Hemophilia B w/ clinically identified inhibitors</b>
Palestine	104	10	27	1
Panama	237	12	25	0
Paraguay	434	18	14	7
Peru	481	11	68	1
Philippines	889	10	137	1
Poland	2,187	152	375	3
Romania	1,449	103	200	3
Russia	5,063	148	676	2
Serbia	361	16	62	0
Singapore	176	10	28	0
Slovak Republic	485	12	72	1
Slovenia	175	2	21	0
South Africa	1,532	151	285	7
Spain	1,712	93	273	10
Sri Lanka	413	37	113	
Sudan	514	1	104	1
Switzerland	560	17	112	1
Syria	252	24	48	4
Thailand	917	44	112	4
Tunisia	162	7	38	0
Turkey	3,176	279	676	43
United Kingdom	5,330	180	1,128	9
United States	12,667	737	4,000	67
Uruguay	185	3	30	1
Uzbekistan	1,032	73	117	
Venezuela	1,567	83	432	3
Vietnam	1,304	10	291	0
<b>TOTALS</b>	<b>96,740</b>	<b>5,013</b>	<b>20,691</b>	<b>363</b>



**Age groups: hemophilia A** (44 countries did not report age data)

Country	0-4	5-13	14-18	19-44	45+	Age unknown
Albania	7	35	54	125	18	
Argentina	91	278	215	808	405	45
Armenia	5	20	27	120	11	
Australia	134	283	176	674	568	
Austria	10	72	51	202	108	
Bangladesh	9	116	91	126	25	
Belarus	8	66	21	357		
Belgium	23	107	62	280	293	
Belize		7	1	1		
Brazil	486	1,700	1,047	3,999	1,111	
Bulgaria	9	29	34	267	152	
Cambodia	17	25	6	6		
Cameroon	2	21	35	19	0	
Chile	24	173	145	475	206	45
Colombia	21	48	132	387	137	726
Costa Rica	22	35	21	67	15	
Cote d'Ivoire	1	7	12	10	2	0
Cuba	9	41	42	195	41	
Czech Republic	34	79	71	283	248	
Denmark	12	42	31			
Ecuador	27	103	45	174	51	37
Egypt	80	29	3	14		
France	249	714	422	1,837	1,001	
Georgia	13	36	25	101	31	
Greece	16	87	44	310	293	
Guatemala	10	38	18	30	2	
Hungary	31	42	44	414	272	
Iran	166	593	412	2,370	497	
Iraq	110	225	123	155	20	
Ireland	28	89	36	194	104	
Korea, Republic of	73	251	208	783	192	
Latvia	4	15	12	56	28	
Lesotho	0	3	4	4	0	
Lithuania	0	17	20	62	31	
Malaysia	219	203	49	65	23	
Mexico	161	626	422	1,223	242	821
Moldova	7	23	23	110	61	
Nepal	30	88	39	107	11	
Netherlands	16	226	117	360	434	
New Zealand	23	47	24	115	58	
Pakistan	229	387	238	250	37	
Panama	11	34	15	155	22	
Paraguay	29	65	82	190	68	
Philippines	22	234	162	322	54	
Poland	42	171	142	1,183	639	
Portugal	13	54	23	242	134	
Romania	4	99	84	770	423	
Saudi Arabia	56	92	51	59	3	
Senegal	8	30	57	19	2	



<b>Country</b>	<b>0-4</b>	<b>5-13</b>	<b>14-18</b>	<b>19-44</b>	<b>45+</b>	<b>Age unknown</b>
Serbia	17	39	42	159	104	
Slovak Republic	19	47	27	233	159	
Slovenia	9	8	7	100	51	
South Africa	82	250	164	705	285	
Spain	37	167	98	814	448	148
Sri Lanka	45	111	23	19	3	212
Switzerland	15	62	51	227	205	
Syria	24	82	40	96	10	
Turkey	198	864	461	1,282	344	27
United Kingdom	332	693	462	2,077	1,763	
Uruguay	15	40	15	47	30	40
Venezuela	100	184	284	567	284	
<b>TOTALS</b>	<b>3,494</b>	<b>10,352</b>	<b>6,892</b>	<b>26,401</b>	<b>11,759</b>	<b>2,101</b>



**Age groups: hemophilia B** (44 countries did not report age data)

Country	0-4	5-13	14-18	19-44	45+	Age unknown
Albania	2	6	6	11	2	
Argentina	14	51	34	100	50	13
Armenia	1	2	2	13		
Australia	31	71	37	187	122	
Austria	5	8	9	26	18	
Bangladesh	2	16	22	15	2	
Belarus				68		
Belgium	4	16	13	61	69	
Belize		2	1	2		
Brazil	82	339	219	716	228	
Bulgaria	1	2	3	35	10	
Cambodia	4	1	2	1		
Cameroon	3	1	0	0	0	
Chile	10	30	35	62	28	19
Colombia	8	36	26	79	35	127
Costa Rica	2	4	6	15	1	
Cote d'Ivoire	3	3	2	0	0	
Cuba	1	9	8	38	11	
Czech Republic	5	12	9	45	41	
Denmark	5	11	10			
Ecuador	1	13	8	14	7	7
Egypt	28	6	2	5	1	
France	59	162	92	400	217	
Georgia	3	4	3	19	11	
Greece	2	12	3	72	51	
Guatemala	2	4	1		1	
Hungary	3	8	11	100	76	
Iran	25	119	87	537	94	
Iraq	29	59	48	53	19	
Ireland	14	40	16	95	53	
Korea, Republic of	20	73	40	163	41	
Latvia	0	4	0	16	4	
Lesotho	0	0	0	0	0	
Lithuania	2	2	3	11	4	
Malaysia	61	45	6	26	4	
Mexico	24	106	86	201	48	104
Moldova		1	2	4	4	
Nepal	4	12	1	14	1	
Netherlands	1	39	23	65	67	
New Zealand	5	4	2	28	26	
Pakistan	32	66	45	57	3	
Panama	1	7	2	14	1	
Paraguay	2	2	3	5	2	
Philippines	3	35	28	46	11	
Poland	4	39	34	196	100	
Portugal	1	7	3	50	30	
Romania	0	15	5	95	76	
Saudi Arabia	4	26	4	28	3	
Senegal	1	1	3	2		
Serbia	5	9	6	23	19	



<b>Country</b>	<b>0-4</b>	<b>5-13</b>	<b>14-18</b>	<b>19-44</b>	<b>45+</b>	<b>Age unknown</b>
Slovak Republic	3	25	4	36	19	
Slovenia	1	1	0	19	0	
South Africa	14	45	28	132	62	
Spain	5	21	20	129	80	18
Sri Lanka	17	26	7	0	0	63
Switzerland	2	6	10	52	42	
Syria	2	16	9	18	3	
Turkey	45	185	109	248	85	4
United Kingdom	64	127	83	492	362	
Uruguay	1	11	8	3	2	4
Venezuela	27	49	75	150	75	
<b>TOTALS</b>	<b>700</b>	<b>2,052</b>	<b>1,364</b>	<b>5,092</b>	<b>2,321</b>	<b>359</b>



**Age groups: VWD** (44 countries did not report age data)

Country	0-4	5-13	14-18	19-44	45+	Age unknown
Armenia		3	3	4		
Australia	49	240	153	824	638	
Bangladesh	0	0	0	0	0	
Belarus	171					
Belgium	20	179	85	544	354	
Brazil	59	601	459	1,891	830	
Bulgaria	0	4	3	35	26	
Cambodia		1				
Cameroon	1	0	0	0	0	
Colombia	2	14	21	56	33	72
Cote d'Ivoire	0	1	0	1	0	
Cuba	0	2	7	23	33	
Ecuador		14	9	37	12	7
Egypt	10	6				
France	36	189	76	419	297	
Georgia		4	2	7	6	
Greece	10	122	67	271	214	
Guatemala	1	3	4	6	2	
Hungary	14	74	82	696	439	
Iran	64	170	81	536	91	
Iraq	35	40	64	25	4	
Ireland	37	148	70	534	222	
Korea, Republic of	0	17	16	44	9	
Latvia			4	66	28	
Lesotho	0	0	0	1	0	
Lithuania	0	2	8	93	46	
Malaysia	57	114	31	155	21	
Mexico	3	32	15	45	6	76
Moldova			1	1	1	
Netherlands	3	30	37	59	118	
New Zealand	1	26	21	34	32	
Pakistan	48	88	84	55	1	
Panama	25	166	50	92	13	
Paraguay				1		
Philippines	1	6	9	7	0	
Poland	13	157	122	583	272	
Portugal		2	6	18	22	
Romania	0	11	21	241	55	
Saudi Arabia	4	10	34	26	1	
Senegal	2	2	2	2		
Serbia	2	18	9	136	70	
Slovak Republic	7	47	25	266	127	
Slovenia	3	23	11	80	30	
South Africa	4	50	44	233	177	
Spain	4	17	24	295	252	118
Switzerland	2	11	9	50	54	
Syria	3	10	4	12	1	
Turkey	15	137	71	116	20	3
United Kingdom	187	879	742	3,837	3,122	
Venezuela	49	92	140	280	140	
TOTALS	942	3,762	2,726	12,737	7,819	276

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

Country	Total people with hemophilia	Hemophilia HIV +	Hemophilia HCV +	Total people with vWD	vWD HIV+	vWD HCV+
Albania	268	1				
Argentina	2,104	67	630	354	0	10
Armenia	208		48	10	1	3
Australia	2,283	103	643	1,904	4	70
Austria	509	38	146			
Azerbaijan	846	0	592	218		152
Bangladesh	424		1	0		
Belarus	546	0	85	171		1.6
Brazil	10,026	74	400	3,880	1	19
Bulgaria	589	8	173	79	0	50
Cameroon	68	0	2	1	0	2
Colombia	1,920	10	120	208	0	5
Costa Rica	188	14	59	63		
Cote d'Ivoire	48	0	0	2	0	0
Croatia	477	6	198	282	0	25
Czech Republic	833	2	112			
Dominican Republic	245	2		103		
Ecuador	487	0	3	79	0	0
Egypt	5,307	0	26	455	0	0
France	5,153	448	1,668	1,017	14	136
Georgia	276		130	19		3
Germany	4,230	415	3,000	4,674	6	
Greece	890	66	334	684	1	30
Hungary	1,001	32	390	1,305	0	109
Iceland	64	0	9	96	0	0
India	13,453	160		290		
Iran	4,939	49	2,750	942		
Iraq	841	0	187	168	0	30
Ireland	669	36	142	939		11
Israel	520	25	172	2		
Italy	3,270	220	1,156	1,650	7	69
Japan	5,250	786		917	7	
Kazakhstan	1,360	18	60	460		
Korea, Republic of	1,844		780	86		1
Lebanon	165	0	15	63	0	1
Lesotho	15	0		1		
Lithuania	152		57	149		
Macedonia	280		47	40		1
Malaysia	1,141	3	168	440	0	0
Mexico	4,064	22	115	177	1	2
New Zealand	384	5	147	159	0	7
Nicaragua	217	1	75	59	1	75
Oman	93	1	9	262		
Pakistan	268	3	463	182	0	47
Panama	262	15	21	346	0	1
Romania	1,649	1		348		
Saudi Arabia	326	31	88	75		



Country	Total people with hemophilia	Hemophilia HIV +	Hemophilia HCV +	Total people with vWD	vWD HIV+	vWD HCV+
Senegal	123	0	2	8	0	0
Serbia	423	9	129	226	4	11
Singapore	204	0	65	58	0	2
Slovak Republic	557	0	147	472	0	23
Slovenia	196	7	90	147	0	6
South Africa	1,817	64	192	527	0	2
Spain	1,985	464	933	710	31	106
Sudan	618	2	23	54	0	3
Sweden	1,020	34		1,538	0	130
Syria	300	0	50	30	0	7
Thailand	1,029	10	59	65	0	1
Tunisia	250	16	140	76		
United Kingdom	6,460	338		8,773	6	
United States	16,667	1,967	6,284	12,524	26	326
Uruguay	236	1	71	316		
Uzbekistan	1,155	6	300	88		6
Venezuela	1,999	84	354	701	9	25
Vietnam	1,595	1	115	30	0	4
<b>TOTALS</b>	<b>116,786</b>	<b>5,665</b>	<b>24,175</b>	<b>49,702</b>	<b>119</b>	<b>1,513</b>

## Healthcare System

### How are the majority of people with rare bleeding disorders diagnosed?

Fifty-eight countries reported on how patients with rare bleeding disorders are diagnosed. In 70% of these countries severe bleeding symptoms were the first or only step in diagnosis. Other methods of diagnosis include family history and factor assays. Twenty-eight countries report that factor levels below 5% are considered to signify disease.

### 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. Not all HTCs are comprehensive care centers.

Albania	1	Honduras	2	Panama	2
Algeria	10	Hungary	19	Paraguay	1
Argentina	22	Iceland	1	Peru	10
Armenia	1	India	67	Philippines	7
Australia	16	Indonesia	13	Poland	32
Austria	7	Iran	12	Portugal	7
Azerbaijan	1	Iraq	2	Qatar	2
Bahrain	1	Ireland	4	Romania	12
Bangladesh	3	Israel	3	Russia	4
Belarus	7	Italy	52	Saudi Arabia	4
Belize	0	Jamaica	3	Senegal	1
Brazil	44	Japan	9	Serbia	7
Bulgaria	7	Jordan	3	Singapore	3
Cameroon	1	Kazakhstan	0	Slovak Republic	44
Canada	26	Kenya	2	Slovenia	1
Chile	32	Korea, Rep. of	16	South Africa	15
China	31	Kyrgyzstan	6	Spain	38
Colombia	9	Latvia	2	Sri Lanka	2
Costa Rica	1	Lebanon	1	Sudan	1
Cote d'Ivoire	1	Lesotho	1	Sweden	3
Croatia	4	Lithuania	3	Switzerland	12
Cuba	16	Macedonia	1	Syria	3
Cyprus	1	Malaysia	60	Thailand	38
Czech Republic	17	Mexico	75	Tunisia	4
Denmark	2	Moldova	2	Turkey	34
Dominican Republic	1	Mongolia	3	Ukraine	2
Ecuador	10	Nepal	7	United Kingdom	79
Egypt	10	Netherlands	13	United States	127
El Salvador	3	New Zealand	6	Uruguay	21
Eritrea	1	Nicaragua	1	Uzbekistan	1
Estonia	3	Nigeria	3	Venezuela	23
Georgia	3	Norway	1	Vietnam	6
Germany	32	Oman	2	Zimbabwe	2
Greece	5	Pakistan	14		
Guatemala	3	Palestine	6		



**Reported Use of Factor Concentrates: Factor VIII**

Country	Factor VIII total IU	% plasma-derived factor VIII	% recombinant factor VIII	Humanitarian Aid factor VIII	FVIII per capita excluding humanitarian aid	FVIII per capita including humanitarian aid
Albania	2,000,000	NA	NA	800,000	0.328	0.547
Argentina	93,130,000	77%	23%		2.276	
Armenia	448,056	NA	NA	292,056	0.053	0.151
Australia	145,141,000	11%	89%		6.746	
Bangladesh	523,170	67%	33%	173,170	0.002	0.003
Brazil	205,647,270	100%	0%	0	1.023	
Bulgaria	15,000,000	95%	5%	0	2.098	
Cameroon	10,000	0%	100%	10,000	0.000	0.001
Canada	200,562,256	18%	82%	0	5.941	
Chile	36,000,000	94%	6%		2.150	
Colombia	60,000,000	58%	42%	47,692	1.373	1.374
Cote d'Ivoire	36,801	NA	NA	47,301	0.000	0.002
Cuba	2,407,290	98%	2%	38,790	0.207	0.210
Czech Republic	25,800,000	95%	5%	0	2.526	
Dominican Republic	992,815	28%	72%	822,835	0.017	0.101
Ecuador	6,936,384	96%	4%	250,670	0.452	0.469
France	389,703,600	20%	80%		6.084	
Georgia	2,167,520	98%	2%	3,375,161	0.262	0.471
Germany	680,000,000.0	57%	43%		8.264	
Greece	35,805,000	9%	91%	0	3.331	
Honduras	170,062	NA	NA	170,062	0.000	0.021
Hungary	73,200,000	73%	27%		7.390	
India	36,984,637	NA	NA	0	0.032	
Iran	120,000,000	96%	4%		1.790	
Iraq	1,800,000	0%	100%	0	0.062	
Ireland	32,032,500	3%	97%	0	7.621	
Japan	319,087,000	31%	69%		2.516	
Kazakhstan (2008)	19,333,604	NA	NA		1.255	
Korea, Republic of	134,826,500	56%	44%	0	2.779	
Lebanon (2008)	1,228,500	90%	10%	236,000	0.247	0.306
Lesotho	163,500	NA	NA	0	0.077	
Lithuania	7,601,000	83%	17%	0	2.144	
Malaysia	14,838,000	99%	1%	0	0.567	
Mexico	65,499,750	99%	1%	70,000	0.582	0.582
Moldova	1,538,072	29%	71%	1,056,072	0.112	0.356
Nepal	449,730	NA	NA		0.016	
Nicaragua	944,194	81%	19%	944,194	0.000	0.157
Nigeria	16,430	NA	NA	16,430	0.000	0.000
Norway (2008)	20,000,000	40%	60%	0	4.291	
Oman (2008)	821,500	100%	0%	0	0.240	
Palestine (2008)	1,850,000	100%	0%	0	0.461	
Panama (2008)	5,067,650	88%	12%	613,400	1.306	1.486
Peru	6,996,250	93%	7%		0.234	
Philippines	1,791,179	59%	41%	786,579	0.010	0.018
Poland	160,000,000	95%	5%	0	4.160	

Country	Factor VIII total IU	% plasma-derived factor VIII	% recombinant factor VIII	Humanitarian Aid factor VIII	FVIII per capita excluding humanitarian aid	FVIII per capita including humanitarian aid
Portugal	37,766,250	42%	58%		3.527	
Romania	11,000,000	80%	20%	150,000	0.489	0.496
Russia	538,216,000	92%	8%	0	3.861	
Saudi Arabia	7,187,750	99%	1%		0.246	
Senegal	56,000	66%	34%	27,000	0.002	0.004
Serbia	10,874,250	100%	0%		1.481	
Slovak Republic	27,500,000	96%	4%	0	5.027	
Slovenia	11,048,973	33%	66%	0	5.516	
South Africa	43,034,100	92%	8%	0	0.876	
Spain	205,107,000	40%	60%		5.061	
Sri Lanka	2,705,080	NA	NA	0	0.126	
Sudan	4,523,305	100%	0%	0	0.110	
Sweden	81,477,000	14%	86%		8.979	
Switzerland	29,600,000	24%	76%	0	3.883	
Syria	4,800,000	100%	0%	191,400	0.208	0.216
Tunisia (2008)	3,736,000	97%	3%	100,000	0.347	0.356
Turkey	107,447,750	NA	NA		1.381	
United Kingdom	388,046,799	11%	89%	0	6.332	
United States	1,600,000,000	31%	69%		5.157	
Uruguay	7,000,000	100%	0%	0	1.994	
Uzbekistan	533,770	9%	91%	53,370	0.017	0.019
Venezuela	52,200,000	29%	71%		1.917	
Vietnam	2,750,000	100%	0%	65,100	0.030	0.031
Zimbabwe	211,000	19%	81%	211,000	0.000	0.019

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 2009 while others report the amount *purchased*. Where available the percentage of plasma-derived and recombinant product used is reported. The per capita number divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients. Please note that some FVIII products are used in the treatment of von Willebrand disease and not for hemophilia A.

**Reported Use of Factor Concentrates: Factor IX**

Country	Factor IX total IU	% plasma-derived factor IX	% recombinant factor IX	Humanitarian aid factor IX	FIX per capita excluding humanitarian aid	FIX per capita including humanitarian aid
Albania	400,000	NA	NA	180,000	0.06012	0.10930
Argentina	11,080,000	90%	10%		0.27081	
Armenia	22300	NA	NA	22,300	0.00000	0.00752
Australia	25,453,250	10%	90%		1.18301	
Bangladesh	33,450	100%	0%	33,450	0.00000	0.00021
Brazil	41,687,000	100%	0%	0	0.20729	
Bulgaria	1,000,000	100%	0%	0	0.13988	
Cameroon	1,000	0%	100%	1,000	0.00000	0.00005
Canada	39,861,108	87%	13%	0	1.18073	
Colombia	10,000,000	60%	40%	4,972	0.22884	0.22895
Cote d'Ivoire	25,538	NA	NA	25,538	0.00000	0.00121
Cuba	137,500	100%	0%		0.01201	
Czech Republic	2,700,000	NA	NA	0	0.26440	
Dominican Republic	43,930	68%	32%	43,930	0.00000	0.00449
Ecuador	1,571,429	100%	0%		0.10625	
France	57,668,950	40%	60%		0.90026	
Georgia	700,000	NA	NA		0.15215	
Germany	90,000,000.0	90%	10%		1.09379	
Greece	5,496,400	10%	90%	0	0.51130	
Honduras	68,400	NA	NA	68,400	0.00000	0.00856
Hungary	4,900,000	100%	0%		0.49467	
India	9,637,107	NA	NA	0	0.00822	
Iran	18,000,000	100%	0%		0.26851	
Iraq	3,500,000	0%	100%	0	0.12092	
Ireland	8,912,250	0%	100%	0	2.12035	
Japan	41,300,000	100%	0%		0.32570	
Kazakhstan	1,548,000	NA	NA		0.10052	
Korea, Republic of	22,696,000	10%	90%	0	0.46787	
Lebanon	661,200	97%	3%	61,200	0.14936	0.16460
Lithuania	1,156,000	93%	7%	0	0.32606	
Malaysia	6,807,500	99%	1%	0	0.26022	
Mexico	9,827,000	100%	0%	10,000	0.08729	0.08738
Moldova	33,450	NA	NA	33,450	0.00000	0.00775
Nepal	26,126	NA	NA		0.00090	
Nicaragua	13,896	100%	0%	13,896	0.00000	0.00232
Nigeria	12,350	NA	NA	12,350	0.00000	0.00008
Oman	111,000	100%	0%	0	0.03247	
Palestine	113,600	100%	0%	0	0.02831	
Panama	290,400	100%	0%		0.08514	
Peru	1,055,000	100%	0%		0.03528	
Philippines	159,940	0%	100%	159,940	0.00000	0.00160
Poland	12,000,000	100%	0%	0	0.31198	
Portugal	6,595,000	75%	25%		0.61590	
Russia	63,206,350	NA	NA	0	0.45345	

Country	Factor IX total IU	% plasma-derived factor IX	% recombinant factor IX	Humanitarian aid factor IX	FIX per capita excluding humanitarian aid	FIX per capita including humanitarian aid
Saudi Arabia	1,681,500	100%	0%		0.05757	
Senegal	12,000	100%	0%		0.00085	
Serbia	915,500	100%	0%		0.12465	
Slovak Republic	2,800,000	100%	0%	0	0.51185	
Slovenia	655,500	100%	0%	0	0.32724	
South Africa	5,033,000	100%	0%	0	0.10249	
Spain	24,973,500	50%	50%		0.61625	
Sri Lanka	60,000	NA	NA	0	0.00279	
Sudan	459,000	100%	0%	0	0.01117	
Sweden	13,945,000	51%	49%		1.53680	
Switzerland	5,400,000	91%	9%	0	0.70834	
Syria	450,000	100%	0%	78,000	0.01676	0.02027
Tunisia	629,000	100%	0%	0	0.05998	
Turkey	16,304,000	NA	NA		0.20955	
United Kingdom	70,872,248	8%	92%	0	1.15644	
United States	250,100,000	0%	100%		0.80617	
Uruguay	800,000	100%	0%		0.22790	
Venezuela	6,700,000	100%	0%		0.24611	

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 2009 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

Organization name	
Address	
City	
State, Province, Region, Prefecture, County	
Postal/ZIP Code	
Country	
Phone	
Fax	
E-mail	
Website	

### B. Identified patients

(Please DO NOT estimate or guess)	Number	Not known
1. Number of identified people with <b>hemophilia A and B</b> (PWH)		<input type="checkbox"/>
2. Number of identified people with <b>von Willebrand disease</b> (vWD)		<input type="checkbox"/>
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		<input type="checkbox"/>

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

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

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

Age group	Number with hemophilia A	Number with hemophilia B	Number with VWD
0-4 years old			
5 - 13 years old			
14 - 18 years old			
19 - 44 years old			
45 years or older			
No age data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**6. Type of hereditary bleeding disorder**

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

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

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

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



**9. Number of severe VWD patients**

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"/>

**10. 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
Hemophilia A		<input type="checkbox"/>
Hemophilia B		<input type="checkbox"/>

**11. Products used to treat hemophilia: What percentage of patients is treated with the following products?**

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
Recombinant	%
DDAVP (Desmopressin)	%

**12. Products used to treat vWD: What percentage of patients is treated with the following products?**

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
DDAVP (Desmopressin)	%

**13. HIV and hepatitis C infection among living people with hemophilia**

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

**14. HIV and hepatitis C infection among living people with von Willebrand disease**

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

**15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2009)**

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other inherited bleeding disorders
Bleeding			
HIV			
Liver disease			
Other causes			

**C. Hemophilia Care System in Your Country**

16. How many <b>hemophilia treatment centres</b> are there in your country?	
Percentage of hemophilia patients with access to hemophilia treatment centres:	

**D. The Cost and Use of Factor Concentrates**

17. Annual usage of factor concentrates	Factor VIII	Factor IX	Not known
How many international units (IU) of factor concentrates were used in your country in 2009?			<input type="checkbox"/>
How many international units of <b>plasma-derived</b> concentrates were used in your country in 2009?			<input type="checkbox"/>
How many international units of <b>recombinant</b> concentrates were used in your country in 2009?			<input type="checkbox"/>
How many international units were <b>humanitarian aid</b> ?			<input type="checkbox"/>

**18. Factor VIII Concentrates used in 2009**

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

Currency:

Tax included? No  Yes  Tax rate:

Used	Brand Name	Manufacturer	Price per IU
<input type="checkbox"/>	Aafact	Sanquin	
<input type="checkbox"/>	Advate rAHF PFM	Baxter Bioscience	
<input type="checkbox"/>	Alphanate	Grifols	
<input type="checkbox"/>	Amofil	Sanquin OY	
<input type="checkbox"/>	Beriate P	CSL Behring	
<input type="checkbox"/>	BIOSTATE	CSL Bioplasma	
<input type="checkbox"/>	Conco-eight-HT	Benesis	
<input type="checkbox"/>	Confact F	Kaketsuken	
<input type="checkbox"/>	Cross Eight M	Japanese Red Cross	
<input type="checkbox"/>	Emoclot D.I.	Kedrion	
<input type="checkbox"/>	FACTANE	LFB	
<input type="checkbox"/>	Factor 8 Y	BioProducts Lab.	





<input type="checkbox"/>	Faktor VIII SDH Intersero	Intersero	
<input type="checkbox"/>	Fanhdi	Grifols	
<input type="checkbox"/>	GreenEight	GreenCross	
<input type="checkbox"/>	GreenMono	Greencross Corp	
<input type="checkbox"/>	Haemate P (= Haemate HS)	CSL Behring	
<input type="checkbox"/>	Haemoctin SDH	Biotest	
<input type="checkbox"/>	Haemosolvate Factor VIII	National Bioproducts	
<input type="checkbox"/>	Helixate NexGen = Helixate FS	CSL Behring	
<input type="checkbox"/>	Hemofil M AHF	Baxter BioScience	
<input type="checkbox"/>	HEMORAAS SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-HP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-IP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	Humate P	CSL Behring	
<input type="checkbox"/>	Immunate	Baxter BioScience	
<input type="checkbox"/>	Koate DVI	Talecris	
<input type="checkbox"/>	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
<input type="checkbox"/>	Monoclate P	CSL Behring	
<input type="checkbox"/>	Octanate	Octapharma	
<input type="checkbox"/>	Octanativ-M	Octapharma	
<input type="checkbox"/>	Optivate	Bio Products Laboratory	
<input type="checkbox"/>	Recombinate rAHF	Baxter BioScience	
<input type="checkbox"/>	ReFacto	Wyeth	
<input type="checkbox"/>	Replenate	Bio Products Laboratory	
<input type="checkbox"/>	Wilate	Octapharma	
<input type="checkbox"/>	Xyntha	Wyeth	

### 19. Factor IX Concentrates

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

Used	Brand Name	Manufacturer	Price per IU
<input type="checkbox"/>	Aimafix	Kedrion	
<input type="checkbox"/>	AlphaNine SD	Grifols	
<input type="checkbox"/>	BeneFIX	Wyeth	
<input type="checkbox"/>	Berinin-P = Berinin HS	CSL Behring	
<input type="checkbox"/>	BETAFACT	LFB	
<input type="checkbox"/>	Christmassin-M	Benesis	
<input type="checkbox"/>	Factor IX Grifols	Grifols	
<input type="checkbox"/>	Faktor IX SDN	Biotest	
<input type="checkbox"/>	Hemo-B-RAAS	Shanghai RAAS	
<input type="checkbox"/>	Immuline	Baxter BioScience	
<input type="checkbox"/>	MonoFIX-VF	CSL Bioplasma	

<input type="checkbox"/>	Mononine	CSL Behring	
<input type="checkbox"/>	Nanotiv	Octapharma	
<input type="checkbox"/>	Nonafact	Sanquin	
<input type="checkbox"/>	Novact M	Kaketsuken	
<input type="checkbox"/>	Octanine F	Octapharma	
<input type="checkbox"/>	Replenine – VF	BioProducts Lab.	

## 20. Prothrombin Complex Concentrates

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

Used	Brand Name	Manufacturer	Price per IU
<input type="checkbox"/>	Bebulin VH	Baxter BioScience	
<input type="checkbox"/>	Beriplex P/N	CSL Behring	
<input type="checkbox"/>	Cofact	Sanquin	
<input type="checkbox"/>	Facnyne	Greencross Corp	
<input type="checkbox"/>	Haemosolvex Factor IX	National Bioproducts	
<input type="checkbox"/>	HT DEFIX	SNBTS	
<input type="checkbox"/>	KASKADIL	LFB	
<input type="checkbox"/>	Octaplex	Octapharma	
<input type="checkbox"/>	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
<input type="checkbox"/>	Profilnine SD	Grifols	
<input type="checkbox"/>	Proplex – T	Baxter BioScience	
<input type="checkbox"/>	Prothrombinex- VF	CSL Bioplasma	
<input type="checkbox"/>	Prothromplex-T	Baxter BioScience	
<input type="checkbox"/>	Prothroras	Shanghai RAAS	
<input type="checkbox"/>	UMAN Complex D.I.	Kedrion	

## 21. Other Products

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

Used	Brand Name	Manufacturer	Price per IU
<input type="checkbox"/>	Clottagen (fibrinogen)	LFB	
<input type="checkbox"/>	Fibrinogen HT	Benesis	
<input type="checkbox"/>	FIBRORAAS (fibrinogen)	Shanghai RAAS	
<input type="checkbox"/>	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
<input type="checkbox"/>	Factor VII	Baxter BioScience	
<input type="checkbox"/>	Factor VII	Bio Products	
<input type="checkbox"/>	FACTEUR VII	LFB	
<input type="checkbox"/>	NovoSeven (=Niasase) (activated factor VII)	NovoNordisk	
<input type="checkbox"/>	Factor X P Behring	CSL Behring	
<input type="checkbox"/>	Factor XI	Bio Products	
<input type="checkbox"/>	HEMOLEVEN (Factor XI)	LFB	



<input type="checkbox"/>	WILFACTIN (Von Willebrand Factor)	LFB	
<input type="checkbox"/>	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	

**Suggestions for next year's survey:**

**Completed by:**

**Date:**

**Contact info:**

**Please return to:** Mark Brooker, WFH Senior Public Policy Officer [mbrooker@wfh.org](mailto:mbrooker@wfh.org)

**Fax:** (514-875-8916)

or return by mail to:

**World Federation of Hemophilia**

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## 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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