

World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2006

Report on the Annual Global Survey 2006 is published by the World Federation of Hemophilia.

All data are provisional.

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World Federation of Hemophilia Global Survey 2006



WFH Global Survey 2006

Introduction to the Report on the WFH Global Survey 2006

Report on the Annual Global Survey 2006 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (vWD), other rare bleeding disorders, and 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 2006 survey is the eighth WFH survey. It gathers data for the years 2004, 2005 and 2006. The survey includes data on more than 200,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 100 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.

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 more detailed numbers on rare bleeding disorders.

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

This report provides information on the use of treatment products. It includes only those countries where the national hemophilia organization provided information. Quantities reported used were not independently verified.



2006 WFH Global Survey Summary

Demographics

Number of countries in this survey: **100**

Percentage of world population covered by 2006 survey: **88%**

Number of people identified with hemophilia A and B (question B1) : **137,352**

Number of people identified with vWD (question B2): **48,276**

Number of people identified with other bleeding disorders (question B3): **19,844**

Total number of people with bleeding disorders identified: **205,472**

Number of people with hemophilia A (question B10): **105,385**

Number of people with hemophilia B (question B11): **21,408**

Number of countries using national registries to report these numbers: **57**

Reported number of PWH infected with HIV: **9,611**

Reported number of PWH infected with HCV: **26,819**

Reported number of patients with VWD infected with HIV: **913**

Reported number of patients with VWD infected with HCV: **1,248**

Factor usage

(69 countries reporting)

Per capita factor VIII usage (GNP above US\$10,000): **4.46 IU**

Per capita factor IX usage (GNP above US\$10,000): **0.78 IU**

Per capita factor VIII usage (GNP between US\$2000-US\$10,000): **0.90 IU**

Per capita factor IX usage (GNP between US\$2000-US\$10,000): **0.20 IU**

Per capita factor VIII usage (GNP below US\$2,000): **0.11 IU**

Per capita factor IX usage (GNP below US\$2,000): **0.003 IU**

Total reported annual global consumption of factor VIII concentrates: **5,125,564,772 IU**

Total reported annual global consumption of factor IX concentrates: **917,694,557 IU**

Countries included in the 2006 WFH Global Survey

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

Population Statistics

Country	B1. # of PWH	B2. # people with vWD	B3. # people with OBD	B4. Source of data
Albania	270		2	Registry
Algeria	1,145	107	148	Other
Argentina	1,933	339		Registry
Armenia	162	2		Survey
Australia	1,708	1,224	249	Registry
Austria	456	30		Survey
Azerbaijan	800	200	4	Registry
Bangladesh	333		6	Registry
Belarus	559			Other
Belgium	831	850	115	Other
Belize	14	3	1	Registry
Bosnia-Herzegovina	140	30		
Brazil	8,169	2,316	333	Other
Bulgaria	572	69	27	Registry
Canada	2,921	2,564	870	Registry
Chile	1,027			Registry
China	5,044			Survey
Colombia	1,520	127	135	Registry
Costa Rica	167			Registry
Croatia	454	236	138	Registry
Cuba	364		248	Registry
Cyprus	103	12	5	Other
Denmark	445	334	109	Survey
Dominican Republic	317	58	61	Survey
Ecuador	356	42	12	Registry
Egypt	4,135	396	801	Registry
El Salvador	254	15	7	Other
Eritrea	36			Registry
Estonia	39	33	3	
Finland	298	1,700		Registry
France	4,026	537	185	Survey
Georgia	218	12	12	Registry
Germany	5,000	3,100		
Greece	841	712	142	Survey
Guatemala	123	14	72	Survey
Honduras	194	2	5	Survey
Hungary	976	1,303	467	Registry



Country	B1. # of PWH	B2. # people with vWD	B3. # people with OBD	B4. Source of data
Iceland	59	53	12	Registry
India	12,800			Registry
Indonesia	1,130	27	2	Registry
Iran	4,823	720	1,298	Registry
Iraq	700	135	137	
Ireland	577	616	310	Registry
Israel	473			Survey
Italy	3,270	1,650	700	Registry
Jamaica	108	16	13	Registry
Japan	4,942	805	380	Survey
Jordan	248		45	Registry
Kenya	452	17	5	Other
Korea	1,724	94	55	Registry
Kuwait				
Latvia	123	68	1	Survey
Lebanon	110	38	16	Other
Lesotho	16	2		Survey
Lithuania	149	120	30	Registry
Macedonia	208	18		Survey
Malaysia	1,034	355	324	Registry
Malta	15		4	
Mexico	3,351	87		Other
Moldova	194			Survey
Mongolia	40	1		Registry
Nepal	195			Registry
Netherlands	1,600			Registry
New Zealand	530	143	25	Other
Nicaragua	227	37	5	Survey
Nigeria	42	3	4	Other
Norway	379	823	41	Registry
Pakistan	1,450	37	50	Survey
Palestine	132	7	50	Registry
Panama	243	286	14	Registry
Peru	509	90	14	Registry
Philippines	954	26		Registry
Poland	2,423	929	319	Registry
Portugal	639	48	14	Other
Qatar	112	7	62	Registry
Romania	1,500	281	50	Registry





Country	B1. # of PWH	B2. # people with vWD	B3. # people with OBD	B4. Source of data
Russia	5,056	1,196	930	Registry
Saudi Arabia	170	42		Other
Senegal	104	4	3	Survey
Serbia	451	208	14	Registry
Singapore	204	58	85	Registry
Slovak Republic	519	367	599	Registry
Slovenia	175	63	73	Registry
South Africa	1,689	503	208	Registry
Spain	1,920	683	289	Registry
Sri Lanka	231	4		Other
Sudan	359	23	27	Registry
Sweden	731			
Switzerland	622	106	53	Registry
Thailand	1,244	68	46	Registry
Tunisia	270	65		Survey
Turkey	2,763	206	359	Registry
Ukraine				
United Kingdom	7,429	8,583	6,651	Registry
United States	15,575	11,496	1,610	Survey
Uruguay	199			Registry
Uzbekistan	1,138	86	33	Registry
Venezuela	1,723	578	581	Registry
Viet Nam	1,047	30	146	Other
Zimbabwe	302	1		Registry
TOTALS	137,352	48,276	19,844	



**Demographic Details**

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

Country	B10. Hemophilia A	B11. Hemophilia B	B12. Hemophilia type unknown	B13. von Willebrand disease	B14a. Factor I deficiency	B14b. Factor II deficiency	B14c. Factor V deficiency	B14d. Factor V + VIII deficiency	B14e. Factor VII deficiency	B14f. Factor X deficiency	B14g. Factor XI deficiency	B14h. Factor XIII deficiency	B14i.1 Glanzmann's thrombasthenia	B14i.2 Bernard Soulier Syndrome	B14i.3 Platelet disorders: other	B14j. Oth. hereditary bleeding disorders
Albania	240	30							2							2
Algeria	936	191	16	113	31	2	14	5	36	9	7	2	23	7		
Argentina	1,700	233	178	339												
Armenia	157	5		2												
Australia	1,380	328	0	1,224	0	0	6	0	26	6	81	11				92
Austria	350	53	53	30												
Azerbaijan																
Bangladesh	289	44										1	5			
Belarus	463	96														
Belgium																
Belize	11	3		3												1
Bosnia-Herzegovina	100	10		30												
Brazil	6,887	1,282	206	2,316			38	12	99	20	34	18				82
Bulgaria	507	65	2	69	10	1			10	3	1					
Canada	2,349	572	0	2,564	71	6	30	6	153	26	211	41	0	34	20	272
Chile	897	129	1													
China																
Colombia	1,161	247	112	127	17	9	2	8	13	1	8	4	15	3		23
Costa Rica	139	28							2	1	2	3				
Croatia	374	80	0	11	11	0	8	23	10	5	10	7	37	0	0	1





Country	B10. Hemophilia A	B11. Hemophilia B	B12. Hemophilia type unknown	B13. von Willebrand disease	B14a. Factor I deficiency	B14b. Factor II deficiency	B14c. Factor V deficiency	B14d. Factor V + VIII deficiency	B14e. Factor VII deficiency	B14f. Factor X deficiency	B14g. Factor XI deficiency	B14h. Factor XIII deficiency	B14i.1 Glanzmann's thrombasthenia	B14i.2 Bernard Soulier Syndrome	B14j3 Platelet disorders: other	B14j. Oth. hereditary bleeding disorders
Cuba	303	61			2	0	0	1	0	0	2	1		0		0
Cyprus	52	61		12												5
Denmark	352	93	0	334	0	1	2	0	35	7	6	9	22			
Dominican Republic				58			0	1		12				1		
Ecuador	322	34	23	42	1				3	1	5	1				
Egypt	3,224	801		396	100		134	6	60	68	78	11	23	2	298	24
El Salvador	229	25		15												5
Eritrea	31	5														
Estonia	36	3		33												3
Finland	234	64	0	1,700	14	1	5	0	4	4	2	13				
France	3,302	724	0	537	24	0	22	4	52	11	54	18	0			
Georgia	186	35	0	12								1				12
Germany	4,055	745	1,200	3,100												
Greece	714	127		712	8		3	1	33	4	25	10	18	14		26
Guatemala	114	9		14												72
Honduras	179	15		2								2	3			
Hungary	789	187		1,303	14	5	16		166	18	61	3		7	2	28
Iceland	57	2	0	53									12			
India	10,112	1,792	896													
Indonesia	220	31	879													
Iran	3,980	843		720	70	13	64	124	195	91	50	124	136	14		327
Iraq	525	175		135	26		1		34	5	1	5				65
Ireland	385	192		616			34		35	54	65	3	41	3	2	73
Israel	372	71	30													
Italy	2,697	573	21	1,650	49	14	73	23	308	54	156	21	115			45
Jamaica	101	8	0	16												12
Japan	4,051	891		805	54	5	19	6	43	15	21	50				
Jordan	202	46					1		51	3	3	6				
Kenya	387	43	5	17												
Korea	1,423	301	2	94	4		2	6	16		11	3	11			
Kuwait																
Latvia	103	20		68					1							
Lebanon	88	22		38												16
Lesotho	16	0		2												
Lithuania	128	21	0	120	0	0	2	0	21	1	1	3	0	0	0	10





Country	B10. Hemophilia A	B11. Hemophilia B	B12. Hemophilia type unknown	B13. von Willebrand disease	B14a. Factor I deficiency	B14b. Factor II deficiency	B14c. Factor V deficiency	B14d. Factor V + VIII deficiency	B14e. Factor VII deficiency	B14f. Factor X deficiency	B14g. Factor XI deficiency	B14h. Factor XIII deficiency	B14i.1 Glanzmann's thrombasthenia	B14i.2 Bernard Soulier Syndrome	B14j3 Platelet disorders: other	B14j. Oth. hereditary bleeding disorders
Macedonia	149	59		18												
Malaysia	877	157		355	4	2	13		50	12	26	11		36		70
Malta	12	3														4
Mexico	2,902	449	274	87												
Moldova																
Mongolia	35	5	0	1												
Nepal	165	30	1						1	3			1			
Netherlands	1,500	100														
New Zealand	446	84		143									25			
Nicaragua	205	22		37	4											1
Nigeria	32	5	5	3												
Norway	283	96		823	3	0	4		25							
Pakistan	1,320	130		37												
Palestine	105	27		9	12		3			4				26	1	48
Panama	218	25		286					2	10				1	1	
Peru	439	73	75	91	0	0	1	0	4	1	5	1	0	2	0	0
Philippines	788	123	43	26												
Poland	2,069	354		929					155							
Portugal	498	103	38	48	2		3				6	1				2
Qatar	87	25		7	2		6	1	6	2	20	1				
Romania	1,330	170		281	2			2	5							41
Russia	4,381	675		1,196												
Saudi Arabia	129	38	3	42												
Senegal	99	5		4					2							1
Serbia	388	63		208	1			1	4		4	3	1			
Singapore	176	28	0	58	0	0	15	0	9	0	46	3				
Slovak Republic	449	70		367	46	0	32	2	462	9	21	3		10	6	11
Slovenia	159	16	0	63												73
South Africa	1,426	263		503	9	0	41	4	18	10	30	6	8	11	23	48
Spain	1,645	275		683	15	3	14	3	22	8	24	20	6	16		158
Sri Lanka				4												
Sudan	332	27		23	3		3		2	3		6		7		
Sweden																
Switzerland	516	106	0	53	9	0	0	4	20	3	3	14				0
Thailand	1,102	142		68					11				33			





Country	B10. Hemophilia A	B11. Hemophilia B	B12. Hemophilia type unknown	B13. von Willebrand disease	B14a. Factor I deficiency	B14b. Factor II deficiency	B14c. Factor V deficiency	B14d. Factor V + VIII deficiency	B14e. Factor VII deficiency	B14f. Factor X deficiency	B14g. Factor XI deficiency	B14h. Factor XIII deficiency	B14i.1 Glanzmann's thrombasthenia	B14i.2 Bernard Soulier Syndrome	B14j3 Platelet disorders: other	B14j. Oth. hereditary bleeding disorders
Tunisia	219	51		62	26			3	25	5		12	138	4		
Turkey	2,276	487		206		1	6	22	77	39	6	2	8	10	2	32
Ukraine																
United Kingdom	6,137	1,292		8,583	262	13	119	24	532	184	1,612	59	93	45	1,060	
United States	11,900	3,675		11,496	83	52	162		559	89	552	113				
Uruguay	152	9														
Uzbekistan	1,022	116		86		7			3				33	5	1	
Venezuela	1,342	381		578	48	11	17	21	72	78	128	8		15	6	5
Viet Nam	864	183	0	30	0	2	2	15	2	7	1	1	8	23	0	85
Zimbabwe	302	50		1												
Total	105,385	21,408	4,063	46,927	1,037	148	917	328	3,476	886	3,379	635	815	296	1,423	1,774



Patients with clinically identified inhibitors

Country	Hemophila A Total patients	Hemophila A Patients with clinically identified inhibitors	Hemophila B Total patients	Hemophila B Patients with clinically identified inhibitors
Algeria	936	24	191	1
Argentina	1,700	129	233	5
Australia	1,380	48	328	3
Belarus	463	29	96	
Bulgaria	507	29	65	
Canada	2,349	79	572	3
Colombia	1,161	227	247	23
Croatia	374	18	80	1
Egypt	3,224	10	801	
France	3,302	71	724	2
Germany	4,055	104	745	14
Greece	714	21	127	2
Honduras	179	1	15	
Hungary	789	22	187	1
Indonesia	220	50	31	
Iran	3,980	170	843	1
Iraq	525	5	175	
Ireland	385	8	192	1
Italy	2,697	288	573	8
Jordan	202	18	46	0
Korea	1,423	66	301	9
Latvia	103	2	20	1
Lesotho	16	1	0	
Lithuania	128	8	21	0
Malaysia	877	53	157	3
Mexico	2,902	86	449	2
New Zealand	446	39	84	0
Nicaragua	205	5	22	
Norway	283	0	96	9
Palestine	105	1	27	
Panama	218	3	25	0
Peru	439	2	73	0
Philippines	788	11	123	1
Poland	2,069	152	354	3
Russia	4,381	122	675	2



Country	Hemophila A Total patients	Hemophila A Patients with clinically identified inhibitors	Hemophila B Total patients	Hemophila B Patients with clinically identified inhibitors
Serbia	388	14	63	0
Singapore	176	10	28	0
Slovak Republic	449	16	70	1
South Africa	1,426	442	263	62
Spain	1,645	57	275	5
Sudan	332	2	27	
Switzerland	516	19	106	1
Thailand	1,102	35	142	1
Tunisia	219	6	51	0
Turkey	2,276	183	487	32
United Kingdom	6,137	172	1,292	8
United States	11,900	743	3,675	76
Uzbekistan	1,022	34	116	
Venezuela	1,342	225	381	8
Viet Nam	864	7	183	0
Zimbabwe	302	2	50	
TOTAL:	73621	3869	15907	289



HIV and HCV infection

Country	B1. Total people with hemophilia	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Total people with vWD	B28. vWD HIV infection	B29. vWD HCV infection
Albania	270	1				
Algeria	1,145	10	143	107		
Argentina	1,933	75	657	339		
Australia	1,708	107	668	1,224	4	72
Austria	456	55	102	30	1	
Azerbaijan	800	0	24	200		
Bangladesh	333		2		1	
Belize	14	0	0	3	0	0
Brazil	8,169	379	2,165	2,316		
Bulgaria	572	9	516	69	0	50
Canada	2,921	219	837	2,564	6	67
Colombia	1,520	15	80	127	0	3
Costa Rica	167	19	62			
Croatia	454	6	180	236	0	50
Cuba	364	4	125			
Cyprus	103	2	13	12		
Denmark	445	30	87	334	0	1
Dominican Republic	317		1	58		
El Salvador	254	2	1	15		
Estonia	39	0	21	33	0	4
Finland	298	2	137	1,700		
France	4,026	418	1,510	537	11	103
Georgia	218	0	58	12	0	0
Germany	5,000	440	3,000	3,100		
Greece	841	72	365	712	2	33
Guatemala	123	0	26	14	0	0
Hungary	976	10	302	1,303	2	100
Iceland	59	0	9	53		
Indonesia	1,130	4	65	27		
Iran	4,823	200	2,300	720	0	
Iraq	700		182	135		24
Ireland	577	39	217	616		8
Israel	473	27	170			
Italy	3,270	220	1,156	1,650	7	69
Jamaica	108	8	36	16	1	1
Japan	4,942	1,411		805	8	
Korea	1,724	21	616	94	0	4



Country	B1. Total people with hemophilia	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B2. Total people with vWD	B28. vWD HIV infection	B29. vWD HCV infection
Latvia	123		60	68		18
Lebanon	110	2	20	38	0	0
Lesotho	16		0	2	0	0
Lithuania	149	0	38	120	0	2
Macedonia	208	0	24	18	0	1
Malaysia	1,034	12	136	355		1
Mexico	3,351	30	98	87	1	2
Mongolia	40	0	0	1		
Nepal	195		5			
Netherlands	1,600	156	1,000			
New Zealand	530	4	151	143	0	9
Nicaragua	227	1	97	37		
Pakistan	1,450	1	18	37	9	
Palestine	132	0	4	7	0	0
Panama	243	17	21	286	0	0
Peru	509	9	45	90	3	15
Philippines	954	0	2	26	0	0
Poland	2,423	6		929		
Romania	1,500	15	900	281		
Saudi Arabia	170	34	81	42	0	3
Senegal	104	0	2	4	0	0
Serbia	451	86	122	208	4	11
Singapore	204	0	65	58	0	2
Slovak Republic	519	0	159	367	0	23
South Africa	1,689	48	125	503	0	1
Spain	1,920	572	942	683	31	131
Sudan	359	1	25	23		
Thailand	1,244	9	49	68		1
Tunisia	270	16	0	65		
United Kingdom	7,429	2,887	397	8,583	789	6
United States	15,575	1,808	5,679	11,496	24	402
Uruguay	199	2				
Uzbekistan	1,138	2	292	86		5
Venezuela	1,723	87	320	578	9	24
Viet Nam	1,047	1	109	30	0	2
Zimbabwe	302			1		
TOTAL	100,409	9,611	26,819	44,481	913	1,248



Reported Use of Treatment Products

Country	B17. Availability: plasma	B18. Availability: cryo	B19. Availability: pd concentrate	B20. Availability: rec	B21. Availability: DDAVP
Albania	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Algeria	sometimes	Sometimes	always	never	never
Argentina	Never	Rarely	Always	Sometimes	rarely
Armenia	Always	Sometimes	Rarely	Never	Never
Australia	Never	Never	Rarely	Always	Sometimes
Austria	Never	Never	Sometimes	Sometimes	Rarely
Azerbaijan	Always	Rarely	Rarely	Rarely	Never
Bangladesh	Always	Rarely	Sometimes	Sometimes	Never
Belarus	Rarely	Always	Sometimes	Never	Never
Belgium	Never	Never	Always	Always	Rarely
Belize			Always		Sometimes
Bosnia-Herzegovina	Always	Sometimes	Sometimes	Never	Never
Brazil	rarely	rarely	always	sometimes	sometimes
Bulgaria	Never	Never	Always	Rarely	Rarely
Canada	Never	Never	Rarely	Always	Sometimes
Chile	Always	Always	Sometimes	Rarely	Rarely
China	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Colombia		Rarely	Always	Sometimes	Sometimes
Costa Rica		Sometimes	Always	Sometimes	Always
Croatia	Never	Rarely	always	Always	Always
Cuba	Rarely	Sometimes	Sometimes	Sometimes	Rarely
Cyprus			Always	Rarely	
Denmark	Never	Never	Never	Always	Always
Dominican Republic	Rarely	Never	Sometimes	Rarely	Sometimes
Ecuador	Always	Always	Sometimes	Rarely	never
Egypt	Always	Always	Rarely	Rarely	Sometimes
El Salvador	Sometimes	Sometimes	Rarely	Rarely	Never
Eritrea	Never	Never	Never	Sometimes	Never
Estonia	Never	Never	Always	Never	Never
Finland	Never	Never	Always	Always	Rarely
France	Never	Never	Sometimes	Sometimes	Sometimes
Georgia	Rarely	Rarely	Always	Rarely	Rarely
Greece	Never	Never	Rarely	Always	Sometimes
Guatemala		Always	Sometimes	Rarely	
Honduras	Sometimes	Rarely	Always	Rarely	
Hungary	Never	Never	Sometimes	Sometimes	Sometimes

Country	B17. Availability: plasma	B18. Availability: cryo	B19. Availability: pd concentrate	B20. Availability: rec	B21. Availability: DDAVP
Iceland	Never	Never	Never	Always	Sometimes
India	Sometimes	Sometimes	always	Rarely	Rarely
Indonesia	Always	Always	Sometimes	Rarely	Never
Iran	Always	Always	Always	Rarely	Sometimes
Ireland				Always	Always
Israel	Rarely	Rarely	Sometimes	Sometimes	Rarely
Italy	Never	Never	Sometimes	Sometimes	Sometimes
Jamaica	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Japan	Never	Never	Always	Always	Rarely
Jordan	Sometimes	Sometimes	Always	Rarely	
Kenya	Always	Sometimes	Rarely	Sometimes	never
Korea	Never	Never	Always	Always	Always
Kuwait	Never	Never	Always	Never	Never
Latvia	Never	Never	Always	Rarely	Always
Lebanon	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Lesotho			always	never	never
Lithuania	Never	Never	Always	Sometimes	Sometimes
Macedonia	Sometimes	Always	Sometimes	Never	Sometimes
Malaysia	Never	Never	always	never	Sometimes
Malta			Always		
Mexico	Always	Always	always	never	Sometimes
Moldova	Rarely	Always	Sometimes		Sometimes
Mongolia	Always	Always	Never	Never	Never
Nepal	Always	Sometimes	Never	Sometimes	Rarely
Netherlands	Never	Never	Always	Always	Always
New Zealand	Rarely	Never	Sometimes	Sometimes	Sometimes
Nicaragua	Always	Sometimes	Rarely	never	never
Nigeria	Rarely	Rarely	Rarely	Rarely	Rarely
Norway	Never	Never	Always	Always	Always
Pakistan	Sometimes	Sometimes	Always	Sometimes	Sometimes
Palestine	Always	Sometimes	Always	Sometimes	Rarely
Panama	Rarely	Sometimes	always	Rarely	Always
Peru	Sometimes	Sometimes	Always	Never	Rarely
Philippines	Always	Always	Sometimes	Rarely	Never
Poland	Never	Never	always	Never	Rarely
Portugal	Never	Never	Sometimes	Sometimes	Sometimes
Qatar	Sometimes	Sometimes	Sometimes	Always	Sometimes
Romania	Sometimes	Sometimes	Sometimes	Rarely	Rarely

Country	B17. Availability: plasma	B18. Availability: cryo	B19. Availability: pd concentrate	B20. Availability: rec	B21. Availability: DDAVP
Russia	Always	Always	Always	Rarely	Rarely
Saudi Arabia	Never	Never	Always	Never	Sometimes
Senegal	Always	Sometimes	Sometimes	Sometimes	Rarely
Serbia	Rarely	Rarely	Always	Sometimes	Sometimes
Singapore	Never	Never	Always	Sometimes	Never
Slovak Republic	Never	Never	Always	Never	Never
South Africa	Never	Never	always	Rarely	Sometimes
Spain	Never	Never	Always	Always	Always
Sri Lanka	Sometimes	Sometimes	Sometimes		
Sudan	Rarely	Rarely	Always	Rarely	Never
Sweden	Never	Never	Sometimes	Always	Sometimes
Switzerland	Never	Never	Sometimes	Sometimes	Sometimes
Thailand	Always	Always	Sometimes	Rarely	Sometimes
Tunisia	Never	Sometimes	always	Rarely	never
Turkey	Always	Never	Always	Rarely	Always
Ukraine	Sometimes	Sometimes	Rarely	Never	Rarely
United Kingdom	Rarely	Rarely	Sometimes	Sometimes	Sometimes
United States	Rarely	Rarely	Sometimes	Always	Always
Uruguay	Sometimes	Sometimes	Sometimes	Never	Rarely
Uzbekistan	Always	Always	Sometimes		
Venezuela	Never	Never	Sometimes	Sometimes	Sometimes
Viet Nam	Always	Always	Sometimes	Rarely	Rarely
Zimbabwe		Sometimes	Sometimes	never	never

**Healthcare System**

Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Albania	3,130,000	1	150	Clinical symptoms	no	no
Algeria	32,854,000	11	1,145	Factor assay	no	no
Argentina	38,747,000	19		Factor assay	no	yes
Armenia	3,016,000	0		Clotting screening test	no	no
Australia	20,155,000	15	1,708	Factor assay	no	yes
Austria	8,189,000	20	250	Factor assay	no	yes
Azerbaijan	8,411,000	1	150	Factor assay	no	no
Bangladesh	141,822,000	3	339	Factor assay	no	no
Belarus	9,755,000	0	0	Not known	no	no
Belgium	10,419,000	7		Factor assay	no	yes
Belize	270,000	3	14	Factor assay	no	no
Bosnia-Herzegovina	3,907,000			Factor assay	no	no
Brazil	186,405,000	30	11,355	Factor assay	no	no
Bulgaria	7,726,000	6	500	Factor assay	no	yes
Canada	33,390,141	25	6,355	Factor assay	yes	yes
Chile	16,295,000			Factor assay	no	no
China	1,315,844,000	6		Factor assay	no	yes
Colombia	45,600,000	8	1,350	Factor assay	no	no
Costa Rica	4,327,000	1	131	Factor assay	no	yes
Croatia	4,551,000	4	450	Factor assay	no	no
Cuba	11,269,000		303	Factor assay	no	no
Cyprus	835,000	1	64	Factor assay	no	no
Denmark	5,431,000	2	888	Factor assay	no	yes
Dominican Republic	8,895,000	1	212	Factor assay	no	no
Ecuador	13,228,000	2	150	Factor assay	no	no
Egypt	74,033,000	10		Factor assay	no	no
El Salvador	6,881,000	3	274	Factor assay	no	no
Eritrea	4,401,000	1		Factor Assay	no	no
Estonia	1,330,000	3	39	Factor assay	no	no
Finland	5,249,000	1		Factor assay	no	no
France	60,496,000	40	4,018	Factor assay	no	yes
Georgia	4,474,000	3	242	Factor assay	no	no
Germany	82,689,000				no	no
Greece	11,120,000	4	450	Factor assay	no	no
Guatemala	12,599,000	1			no	yes





Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Honduras	7,205,000	2	145	Factor assay	no	no
Hungary	10,098,000	8	2,746	Factor assay	yes	yes
Iceland	295,000	1	30	Factor assay	no	no
India	1,103,371,000			Factor assay	no	no
Indonesia	222,781,000	9	1,130	Clotting screening	no	no
Iran	69,515,000	10	6,841	Factor assay	yes	yes
Iraq	28,807,000	1	972		no	no
Ireland	4,109,086	4	600	Factor assay	yes	yes
Israel	6,725,000	3	473	Factor assay	no	no
Italy	58,093,000	52	5,620	Factor assay	yes	yes
Jamaica	2,651,000	3	109	Factor assay	no	yes
Japan	128,085,000	8		Factor assay	no	yes
Jordan	6053193	3		Factor Assay	no	no
Kenya	34,256,000	1	221	Clotting screening test	no	no
Korea	47,817,000	12		Factor assay	no	no
Kuwait	2,687,000			Factor assay	no	no
Latvia	2,307,000	2	120	Factor assay	no	no
Lebanon	3,577,000	4	110	Factor assay	no	no
Lesotho	3,607,899	1	16	Factor assay	no	no
Lithuania	3,431,000	4		Factor assay	no	no
Macedonia	2,034,000	1	200	Factor assay	no	no
Malaysia	25,347,000	36	20	Factor assay	no	no
Malta	402,000			Not known	no	no
Mexico	107,029,000	52	3,712	Clotting Screening test	no	no
Moldova	4,206,000			Factor assay	no	no
Mongolia	2,646,000	3		Factor assay	no	no
Nepal	27,133,000	6	160	Factor assay	no	no
Netherlands	16,299,000	11	1,600	All	no	yes
New Zealand	4,028,000	6	500	Factor Assay	yes	yes
Nicaragua	5,487,000	1	227	clotting screening	no	no
Nigeria	131,530,000	0		clinical symptoms	no	no
Norway	4,620,000	1	400	Factor assay	yes	yes
Pakistan	157,935,000	10	1,500	Clotting Screening test	no	no
Palestine	3,702,000	6	132	Factor assay	no	no
Panama	3,232,000	2	543	Factor assay	no	no





Country	Population	C1. # HTCs	C2. # people cared for at HTCs	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Peru	27,968,000	10	586	Clotting screening test	no	no
Philippines	83,054,000	4	100	Factor assay	no	no
Poland	38,530,000	32		Factor assay	no	no
Portugal	10,495,000	7		Factor assay	no	yes
Qatar	840,290	2	50	all	no	no
Romania	21,711,000	9	2,033	Factor assay/screening	no	no
Russia	143,202,000	4	1,800	Factor assay	no	no
Saudi Arabia	24,573,000	1	170	Factor assay	no	no
Senegal	11,658,000	1	104	Factor assay	no	no
Serbia	10,503,000	7	300	Factor assay	no	no
Singapore	4,326,000	3	80	Factor assay	no	no
Slovak Republic	5,401,000	44	390	Factor assay	no	yes
Slovenia	19,920,000	1	311	Factor assay	no	no
South Africa	47,432,000	11	831	Factor assay	no	no
Spain	43,064,000	34		Factor assay	yes	yes
Sri Lanka	20,743,000	1		Clotting Screening test	no	no
Sudan	36,233,000	1	200	Factor assay	no	no
Sweden	9,041,000	3		Factor assay	yes	yes
Switzerland	7,252,000	10	678	Factor assay	no	yes
Thailand	64,233,000	33	1,244	Factor assay	no	no
Tunisia	9,673,600	4	150	Factor assay	no	no
Turkey	73,193,000	34	3,328	Factor assay	no	no
Ukraine	46,481,000	2		Factor assay	no	no
United Kingdom	59,668,000	88	22,781	Factor assay	yes	yes
United States	298,213,000	135	28,795	Factor assay	no	yes
Uruguay	3,463,000	14	179	Factor assay	no	no
Uzbekistan	26,593,000	1	537	all	no	no
Venezuela	26,749,000	16	2,000	Factor assay	no	no
Viet Nam	84,238,000	5		Factor assay	no	no
Zimbabwe	13,010,000	2	50	Factor assay	no	no



**Reported Use of Factor Concentrates**

Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
Albania	800,000	300,000					700,000	200,000
Algeria	9,000,000	1,512,000						
Armenia	30,000						30,000	
Australia	93,000,000	15,300,000	26,000,000	5,800,000	6,700,000	9,500,000		
Azerbaijan	416,810						416,810	
Bangladesh	690,815	17,150	591,770	17,150	99,045		138,875	17,150
Belarus	2,795,000	535,000						
Belgium	60,000,000		13,000,000		47,000,000			
Belize	70,000	120,000					20,000	50,000
Bosnia-Herzegovina	2,800,000	150,000	2,800,000	150,000				
Brazil	224,000,000	60,000,000	224,000,000	60,000,000				
Bulgaria	9,180,000	300,000	9,000,000	300,000	180,000			
Canada	143,000,000	38,000,000	8,000,000	4,285,000	130,201,000	32,146,000		
Colombia	34,000,000	2,500,000	33,000,000	900,000	1,000,000	1,600,000		
Costa Rica	6,063,750	3,055,500						
Croatia	11,163,045	1,142,500	9,656,202	1,142,500	1,503,843			
Cuba	262,500	25,000			262,500	25,000		
Dominican Republic	308,366	20,000					205,366	
Ecuador	152,887	85,000					152,887	85,000
Eritrea	149,250				149,250		149,250	
Finland	23,330,500	2,819,750	16,059,250	1,096,500	7,271,250	1,723,250	0	0
France	310,054,750		51,499,000		258,555,750			
Georgia	1,851,175	359,500	1,800,000	308,500			51,175	51,000
Germany	560,000,000	80,000,000						
Greece	28,765,383	4,027,642	3,772,659	268,540	24,992,724	3,759,102		
Honduras	3,188						50,400	34,200
Hungary	51,300,000	4,500,000	49,800,000	4,500,000	1,500,000			
Iceland	2,200,500	20,000			2,200,500	20,000		
India	6,279,875	781,245	4,782,375	781,245	1,497,500		1,700,341	195,525
Indonesia	3,372,800		3,360,000				30,660	32,150
Iran	90,000,000	15,000,000	90,000,000					
Ireland	22,600,000	8,570,000			16,075,250	7,667,500		
Italy	300,000,000	50,000,000	120,000,000	20,000,000	180,000,000	30,000,000		





Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
Japan	291,000,000	38,900,000	114,363,000	38,900,000	17,663,700			
Jordan	1,675,000	200,000					50,400	14,700
Kenya	2,600				2,600		2,600	
Korea	100,667,750	15,779,250	64,279,750	2,296,250	36,388,000	13,482,000		
Latvia	3,534,000	311,500	3,534,000	3,111,500				
Lebanon	2,348,420	729,600	1,408,000	729,600			868,420	
Lesotho	366,500		366,500					
Lithuania	3,774,100	514,650						
Macedonia	900,000	50,000	900,000	50,000			500,000	
Malaysia	10,250,000	5,000,000	10,250,000	5,000,000				
Mexico	52,031,500	10,275,600	52,031,500	10,275,600			105,000	82,000
Moldova	108,000						108,000	
Nepal	327,296	65,505						
New Zealand	20,220,000	3,525,000	650,000	2,400,000	13,000,000	992,000		
Nigeria	50,000				50,000		50,000	
Pakistan	305,979	11,154	180,000				125,979	
Palestine	2,000,000	400,000	2,000,000	400,000			80,000	
Panama	2,775,322	87,500	2,774,250	87,500	1,072		1,072	
Peru	3,000,000	40,000	3,000,000	400,000			52,154	
Philippines	871,694	169,970	857,814	169,970	13,880		99,444	169,970
Poland	60,000,000	6,000,000	60,000,000	6,000,000				
Portugal	31,725,000	5,229,000	15,304,500	4,724,000	16,422,750	505,000		
Romania	8,300,000	5,000,000					25,000,000	5,000,000
Russia	230,000,000	27,006,852	224,127,000	27,006,852	5,873,000			
Senegal	35,000		15,000		20,000		20,000	
Serbia	8,872,750	400,000	8,872,750	400,000				
Singapore	3,250,000	450,000	3,241,000	45,000	9,000			
Slovak Republic	15,900,000	1,300,000	15,900,000	1,300,000				
South Africa	28,559,400	3,005,000	28,559,400	3,005,000				
Spain	161,929,688	27,070,313	56,670,705	9,479,295	105,245,595	17,604,405		
Sudan	3,190,235	264,610	3,168,235	264,610	22,000		22,000	
Sweden	61,249,000	12,598,000	6,026,000	7,993,000	55,223,000	4,605,000		
Switzerland	27,218,750	5,128,200	8,620,500	489,000	18,598,250	4,639,200		
Turkey	70,496,500	8,322,500						
Ukraine	15,000,000		15,000,000				15,000,000	





Country	D1A. Factor VIII total IUs	D1B. Factor IX total IUs	D2A. Plasma-derived factor VIII	D2B. Plasma-derived factor IX	D3A. Recombinant factor VIII	D3B. Recombinant factor IX	D4A. Humanitarian Aid factor VIII	D4B. Humanitarian aid factor IX
United Kingdom	253,275,120	46,026,311	71,050,647	19,930,911	182,224,473	26,095,400		
United States	1,600,000,000	400,000,000					more than 1 million units for Katrina aftermath	
Uruguay	4,145,250	430,000	1,000,000					
Uzbekistan	49,500						49,500	
Venezuela	52,034,500	5,070,000	51,984,500	5,070,000	50,000		50,000	
Viet Nam		40,000						40,000
Zimbabwe	3,187,800						50,400	34,200

Factor Use Per Capita

Country	FVIII per cap	FIX per cap
Albania	0.256	0.096
Algeria	0.274	0.046
Australia	4.614	0.759
Azerbaijan	0.050	
Bangladesh	0.005	0.000
Belarus	0.287	0.055
Belgium	5.759	
Belize	0.259	0.444
Bosnia-Herzegovina	0.717	0.038
Brazil	1.202	0.322
Bulgaria	1.188	0.039
Canada	4.283	1.138
Colombia	0.746	0.055
Costa Rica	1.401	0.706
Croatia	2.453	0.251
Dominican Republic	0.035	0.002
Ecuador	0.012	0.006
Eritrea	0.034	
Finland	4.445	0.537
France	5.125	0.000
Georgia	0.414	0.080
Germany	6.772	0.967
Greece	2.587	0.362
Hungary	5.080	0.446
Iceland	7.459	0.068
Indonesia	0.015	
Iran	1.295	0.216
Ireland	5.500	2.086
Italy	5.164	0.861
Japan	2.272	0.304
Jordan	0.277	0.033
Korea	2.105	0.330
Latvia	1.532	0.135

Country	FVIII per cap	FIX per cap
Lebanon	0.657	0.204
Lesotho	0.102	
Lithuania	1.100	
Macedonia	0.442	0.025
Malaysia	0.404	0.197
Mexico	0.486	0.096
Nepal	0.012	0.002
New Zealand	5.020	0.875
Pakistan	0.002	0.000
Palestine	0.540	0.108
Panama	0.859	0.027
Peru	0.107	0.001
Philippines	0.010	
Poland	1.557	0.156
Portugal	3.023	0.498
Romania	0.382	0.230
Russia	1.606	0.189
Serbia	0.845	0.038
Singapore	0.751	0.104
Slovak Republic	2.944	0.241
South Africa	0.602	0.063
Spain	3.760	0.629
Sudan	0.088	0.007
Sweden	6.775	1.393
Switzerland	3.753	0.707
Turkey	0.963	0.114
Ukraine	0.323	
United Kingdom	4.245	0.771
United States	5.365	1.341
Uruguay	1.197	0.124
Venezuela	1.945	0.190
Zimbabwe	0.245	

**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	

Executives of your association

Function	Name
A11. President/Chairman	
A12. Medical Advisor	
A13. Executive Director	
A14. International Contact	

A15. Number of full time staff working for the association	
A16. Number of active members in your hemophilia association/society	
A17. How many members in your association are medical doctors?	
A18. Does your association have an annual meeting?	<input type="checkbox"/> Yes <input type="checkbox"/> No
A19. If yes, how many people attended this meeting?	
A20. Does your association produce an annual report?	<input type="checkbox"/> Yes <input type="checkbox"/> No

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"/>

B4. What is the source of the numbers provided above?	Check one
Hemophilia registry of PWH and other inherited bleeding disorders in your country	<input type="checkbox"/>
Survey of your country's hemophilia treatment centres	<input type="checkbox"/>
Other (Describe):	<input type="checkbox"/>





B5. Please assess what proportion of your country's patient population is included in the numbers provided for questions B1-3.	<input type="checkbox"/> 0-25% <input type="checkbox"/> 25-50% <input type="checkbox"/> 50-75% <input type="checkbox"/> 75-100%
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Age distribution of people with Hemophilia and von Willebrand disease

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

Type of hereditary bleeding disorders

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

Number of identified people with hemophilia by diagnosis of severity

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

Products used to treat hemophilia

B17. Plasma	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B18. Cryoprecipitate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B19. Plasma-derived concentrate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never





B20. Recombinant	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B21. DDAVP (Desmopressin)	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never

Products used to treat vWD

B22. Plasma	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B23. Cryoprecipitate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B24. Plasma-derived concentrate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
B25. DDAVP (Desmopressin)	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never

HIV and hepatitis C testing among living people with hemophilia

Infectious Disease	Number of people tested	Number of people infected
B26. HIV		
B27. Hepatitis C		

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

Infectious Disease	Number of people tested	Number of people infected
B28. HIV		
B29. Hepatitis C		

Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2006)

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



**Infectious diseases testing and vaccination**

<u>HIV</u>	Yes	No
C6. Are more than 50% of hemophilia A and B patients tested for HIV?	<input type="checkbox"/>	<input type="checkbox"/>
C7. Are more than 50% of people with vWD tested for HIV?	<input type="checkbox"/>	<input type="checkbox"/>
<u>Hepatitis A</u>		
C8. Are more than 50% of people with hemophilia vaccinated against hepatitis A?	<input type="checkbox"/>	<input type="checkbox"/>
C9. Are more than 50% of people with vWD vaccinated against hepatitis A?	<input type="checkbox"/>	<input type="checkbox"/>
<u>Hepatitis B</u>		
C10. Are more than 50% of people with hemophilia tested for hepatitis B?	<input type="checkbox"/>	<input type="checkbox"/>
C11. Have more than 50% of people with hemophilia been vaccinated against hepatitis B?	<input type="checkbox"/>	<input type="checkbox"/>
C12. Are more than 50% of people with vWD tested for hepatitis B?	<input type="checkbox"/>	<input type="checkbox"/>
C13. Have more than 50% of people with vWD been vaccinated against hepatitis B?	<input type="checkbox"/>	<input type="checkbox"/>
<u>Hepatitis C</u>		
C14. Are more than 50% of people with hemophilia tested for hepatitis C?	<input type="checkbox"/>	<input type="checkbox"/>
C15. Are more than 50% of people with vWD tested for hepatitis C?	<input type="checkbox"/>	<input type="checkbox"/>

Home Care

C16. What is the percentage of people with hemophilia using home care (infusing clotting factor concentrates at home)?	Not available	<input type="checkbox"/>
	Less than 10%	<input type="checkbox"/>
	Between 10% to 50%	<input type="checkbox"/>
	More than 50%	<input type="checkbox"/>
C17. What is the percentage of people with vWD using home care (home infusion)?	Not available	<input type="checkbox"/>
	Less than 10%	<input type="checkbox"/>
	Between 10% to 50%	<input type="checkbox"/>
	More than 50%	<input type="checkbox"/>

Treatment products

C18. Who pays for hemophilia treatment products in your country?	(Check any that apply)	If costs are shared, please indicate the percentage paid by each contributor
Government/health ministry	<input type="checkbox"/>	
Private insurance	<input type="checkbox"/>	
Patients/NMO/charitable institutions	<input type="checkbox"/>	

C19. Who is responsible for choosing hemophilia treatment products used in your country?

Government, health ministry or central pharmacy	<input type="checkbox"/>
Hospitals or doctors	<input type="checkbox"/>

C20. How is the hemophilia treatment product bought?

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Central purchasing for the whole country	<input type="checkbox"/>
Purchase through individual distributor	<input type="checkbox"/>
Other (please describe)	<input type="checkbox"/>

Compensation for HCV infection

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

Compensation for HIV infection

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





D. The Cost and Use of Factor Concentrates

Annual usage of factor concentrates	Factor VIII	Factor IX	Not known
D1. How many international units (IU) of factor concentrates were used in your country in 2006?			<input type="checkbox"/>
D2. How many international units of plasma-derived concentrates were used in your country in 2006?			<input type="checkbox"/>
D3. How many international units of recombinant concentrates were used in your country in 2006?			<input type="checkbox"/>
D4. How many international units were humanitarian aid ?			<input type="checkbox"/>

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

Home care: The patient administers treatment product himself/herself in his/her own home.

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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