

World Federation of Hemophilia Report on the GLOBAL SURVEY 2004

Report on the Global Survey 2004 is published by the World Federation of Hemophilia.

All data are provisional. The WFH is grateful to Dr. Bruce Evatt and the Centers for Disease Control and Prevention (U.S.A.) for assistance in analysing the data and developing this report.

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Additional data from *World Development Indicators* World Bank, Washington, DC. 2003.

Please note: This material is intended for general information only. The World Federation of Hemophilia does not endorse particular treatment products or manufacturers; any reference to a product name is not an endorsement by the World Federation of Hemophilia. The WFH is not a regulatory agency and cannot make recommendations relating to safety of manufacturing of specific blood products. For recommendations of a particular product, the regulatory authority in a particular country must make these judgments based on domestic legislation, national health policies and clinical best-practices.

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Introduction to the Report on the WFH Global Survey 2004

Report on the Global Survey 2004 includes selected demographic and other data on people with hemophilia (PWH) and von Willebrand disease (vWD) 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 2004 survey is the sixth WFH survey. Data were collected in 2004 and supplemented with data from previous surveys. The survey includes data on more than 170,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 96 countries.

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

Comments on data collection

Participation in the survey is voluntary and self-reported. 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.

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.

Section G 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.



2004 WFH Global Survey Summary

Demographics

Number of countries in this survey: **96**

Percentage of world population covered by 2004 survey: **85%**

Number of people identified with hemophilia A and B (question B1) : **120,812**

Number of people identified with von Willebrand disease (question B2): **43,334**

Number of people identified with other bleeding disorders (question B3): **11,384**

Total number of people with bleeding disorders identified: **175,530**

Number of people with hemophilia A (question B10): **93,116**

Number of people with hemophilia B (question B11): **18,830**

Number of countries using national registries to report these numbers: **40**

Reported number of people with hemophilia infected with HIV: **6,048**

Reported number of people with hemophilia infected with hepatitis C: **26,020**

Factor usage

(49 countries reporting)

Per capita factor VIII usage (Gross National Product per capita above US\$10,000): **5.32 IU**

Per capita factor IX usage (GNP above US\$10,000): **0.72 IU**

Per capita factor VIII usage (GNP between US\$2000-US\$10,000): **0.75 IU**

Per capita factor IX usage (GNP between US\$2000-US\$10,000): **0.13 IU**

Per capita factor VIII usage (GNP below US\$2,000): **0.08 IU**

Per capita factor IX usage (GNP below US\$2,000): **0.02 IU**

Total reported consumption of factor VIII concentrates: **1,576,859,835 IU**

Total reported consumption of factor IX concentrates: **236,679,516 IU**



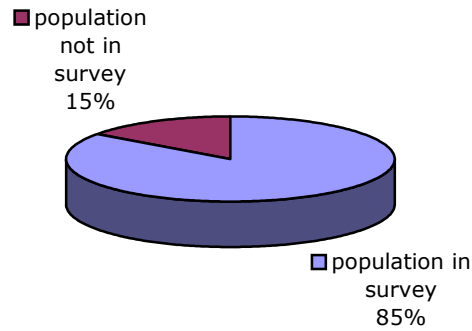
Countries included in the 2004 WFH Global Survey

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

*All data collected in 2004 except: * collected in 2002 and † collected in 2003.*

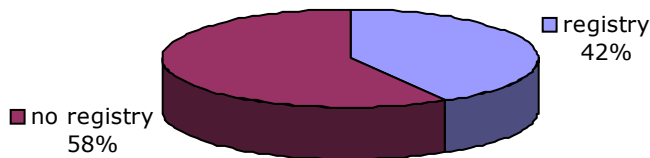


1. World population covered by survey



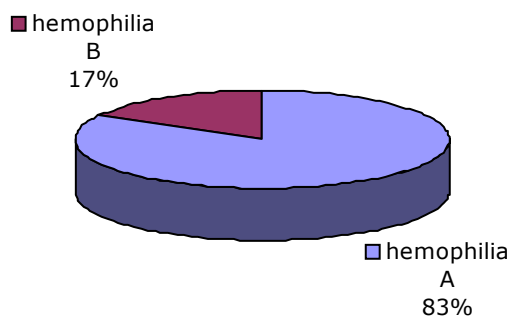
1. The world population is approximately 6.2 billion. Countries with a total population of over 5 billion are included in this survey.

2. Countries using a registry



2. Of the 96 countries in this survey, 40 used a patient registry to report the number of people with bleeding disorders.

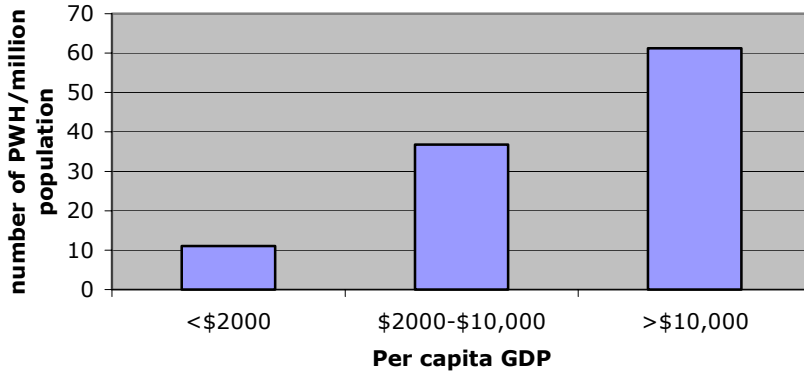
3. Diagnosis hemophilia A or B



3. This proportion of hemophilia A to hemophilia B has been consistent in every survey year.

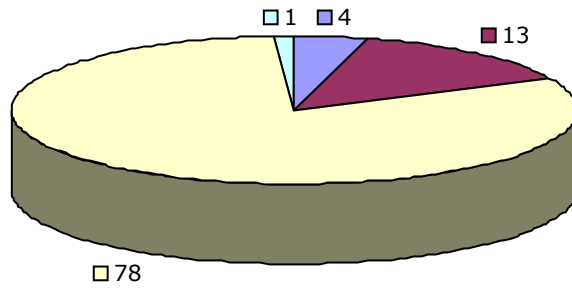


4. Relationship of economic capacity to number of people with hemophilia



4. In general, more people with hemophilia are identified in countries with higher per capita national incomes and people with hemophilia have longer life expectancies the higher the per capita GDP.

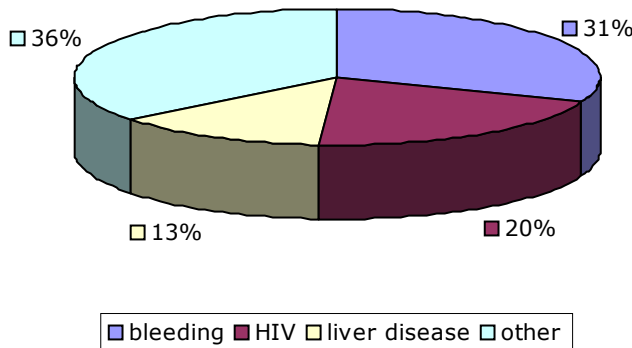
5. Method of diagnosis



5. 80% of respondents now report that factor assays (the state of the art) are the usual method of diagnosis.

■ Clinical symptoms ■ Clotting screening test ■ Factor assay ■ Not known

6. Cause of death

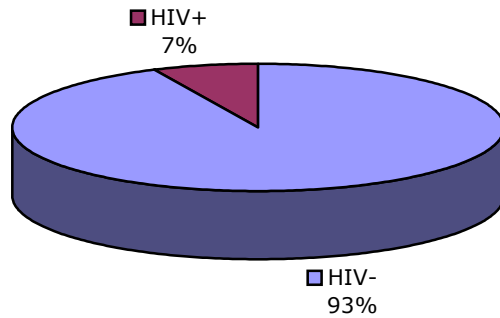


6. A total of 469 deaths were reported in the 2004 survey.

■ bleeding ■ HIV ■ liver disease ■ other

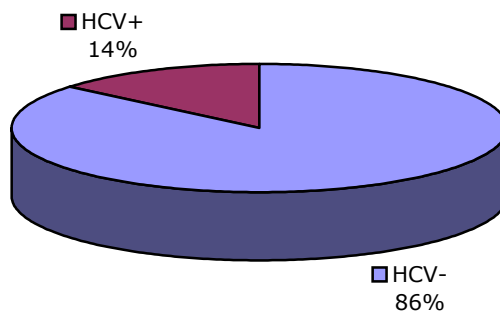


7. Proportion of people with hemophilia HIV-/+



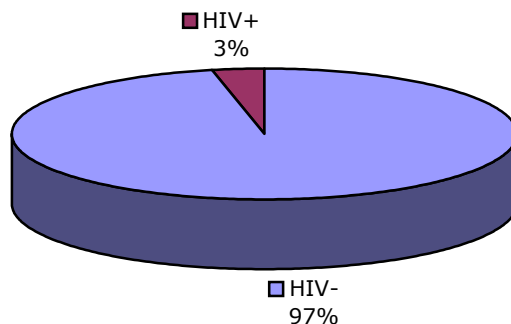
7. This figure uses data only from countries that reported both the total number of people with hemophilia tested for HIV and the number of those infected with HIV.

8. Proportion of people with hemophilia HCV-/+



8. This figure uses data only from countries that reported both the total number of people with hemophilia tested for HCV and the number of those infected with HCV.

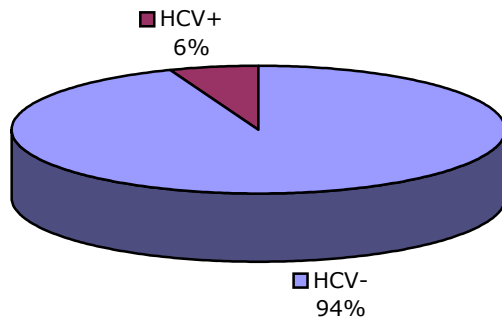
9. Proportion of people with VWD HIV-/+



9. This figure uses data only from countries that reported both the total number of people with von Willebrand disease tested for HIV and the number of those infected with HIV.

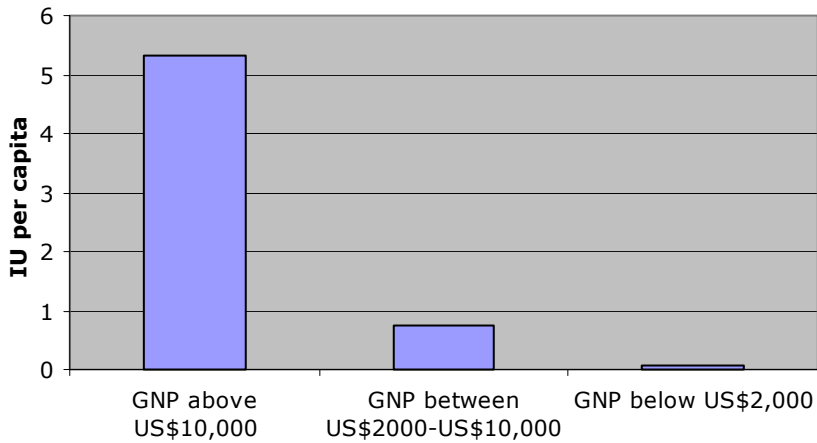


10. Proportion of people with vWD HCV-/+



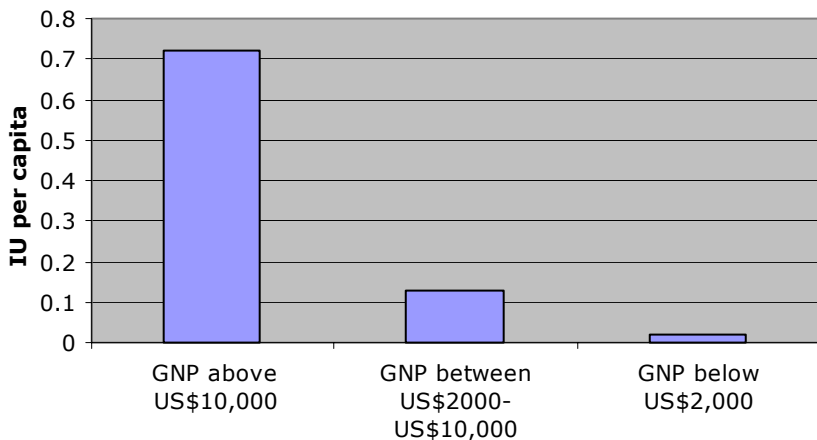
10. This figure uses data only from countries that reported both the total number of people with vWD tested for HCV and the number of those infected with HCV.

11. Per capita factor VIII usage



11. This figure uses data only from the 49 countries which reported total factor VIII usage.

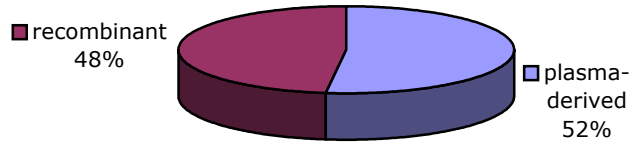
12. Per capita factor IX usage



12. This figure uses data only from the 49 countries which reported total factor IX usage.

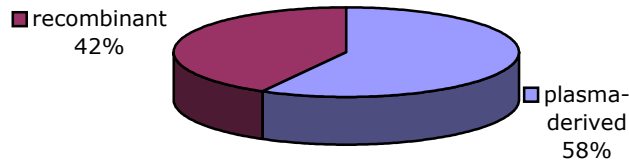


13. Factor VIII ratio plasma-derived to recombinant



13. This figure uses data only from the 49 countries that reported on the breakdown between plasma-derived and recombinant consumption.

14. Factor IX ratio plasma-derived to recombinant



14. This figure uses data only from the 49 countries that reported on the breakdown between plasma-derived and recombinant consumption.

B. Population statistics

Country	Population	Healthcare spending, % of GNP	B1. Number of people with hemophilia	B2. Number of people with vWD	B3. Number of people with other bleeding disorders	B4. Source of data
Albania	3164400	3.4	275			Registry
Algeria	30835000	3.6	977			Survey
Argentina	37488000	8.6	1940			Registry
Armenia	3088000	7.5	162	2		Survey
Australia	19182000	8.3	1070	804	289	Registry
Austria	8132000	8.0	456	30		Survey
Azerbaijan	8116110	0.9	812	190	4	Registry
Bangladesh	133345200	3.8	240	0	2	Registry
Belarus	9881000	5.4	560	800		
Belgium*	10286000	8.7	762	553	49	Survey
Belize	247100	4.6	14	3	1	Registry
Bolivia*	8515200	6.7	14			
Bosnia-Herzegovina	4060000	4.5	140	30		
Brazil	172386000	8.3	6297	886	464	Other
Bulgaria	7913000	3.9	598	56	17	Registry
Canada	31081900	9.1	2772	2156	587	Registry
Chile*	15402000	7.2	1027			Registry
China	1271850000	5.3	4131	227		Survey
Colombia	43035200	9.6	1356	110	145	Survey
Costa Rica	3873000	6.4	163			Survey
Croatia*	4380780	10.0	388	163	57	Survey
Cuba	11188000	6.8	354			Registry
Cyprus	11230000	6.8	103	12	5	Other
Denmark	5359000	8.3	424	314	110	Survey
Dominican Republic*	8505200	6.3	186	9		Survey
Ecuador	13029000	4.1	210	40	20	Survey
Egypt	65176900	3.8	3547	341	652	Other
El Salvador	6400000	8.8	254	15	7	Other
Eritrea	4389000	5.6	23			Other
Estonia*	1364000	6.1	39	33	3	
Finland†	5188000	6.6	280	1589	191	Registry
France	59725000	9.4	4000			
Georgia	5224000	7.1	207	12	10	Registry
Germany	82333000	10.6	4800	3100		Registry
Greece	10590870	8.3	827	514	126	Survey
Guatemala	12307000	4.7	123	14	72	Other

B. Population statistics



World Federation of Hemophilia Global Survey 2004

Country	Population	Healthcare spending, % of GNP	B1. Number of people with hemophilia	B2. Number of people with vWD	B3. Number of people with other bleeding disorders	B4. Source of data
Honduras	6584700	6.8	155			Survey
Hungary	10187000	6.8	1094	1416	551	Registry
Iceland	282000	8.9	58		12	Registry
India	1032355000	4.9	6287			Survey
Indonesia	208981100	2.7	205	27	2	Registry
Iran	64528200	5.5	4094	440	328	Survey
Iraq	24700000	3.3	624	80	96	Survey
Ireland	3839000	6.7	545	555	285	Registry
Israel	6362950	10.9	430			Survey
Italy	57948000	8.1	5319	2275	1488	Registry
Jamaica	2590000	5.5	108	16	13	Registry
Japan†	126870000	7.8	4683	723	337	Other
Kenya	30735800	8.3	425	13	2	Registry
Korea	43343000	6.0	1565	91	32	Registry
Latvia	2359000	5.9	103	39		Survey
Lebanon	4384700	12.4	110	38	16	Other
Lithuania†	3482000	6.0	132	73	20	Survey
Macedonia	2035000	6.0	208	18		Survey
Malaysia	23802400	2.5	895	266	243	Registry
Malta*	395000	8.8	15		4	
Mexico	99419700	5.4	2542	32		Other
Moldova	4270000	3.5	194			Survey
Mongolia	2421400	6.6	40	1		Registry
Nepal*	23584700	4.2	139		2	Survey
Netherlands	16039000	8.1	1600			
New Zealand	3849000	8.0	280	95	6	Registry
Nicaragua*	5205000	4.4	164	22	8	Survey
Norway†	4513000	7.8	362	710	44	Registry
Pakistan	141450100	4.1	575	432		Survey
Palestine	1300000		125	5	48	Registry
Panama	2897000	7.6	241	149	6	Other
Peru	27148000	4.7	456	38	9	Registry
Philippines	78317000	3.4	787	11	44	Registry
Poland†	38641000	6.0	2227	670	138	Registry
Portugal	10024000	8.2	590	51	10	Other
Romania†	22408000	2.9	1414	214	40	Survey
Russia	144752000	5.3	7875	3380		Other



B. Population statistics



World Federation of Hemophilia Global Survey 2004

Country	Population	Healthcare spending, % of GNP	B1. Number of people with hemophilia	B2. Number of people with vWD	B3. Number of people with other bleeding disorders	B4. Source of data
Saudi Arabia	21408470	5.3	170	42		Other
Senegal	10,048,000	4.6	137		2	Survey
Serbia	10651000	5.6	488	193	20	Registry
Singapore*	4131000	3.5	178	48	65	Survey
Slovak Republic	5404000	5.9	502	332	524	Registry
Slovenia†	19920000	8.6	175	63	73	Registry
South Africa	43240000	8.8	1579	463	206	Registry
Spain	41117000	7.7	1864	673	220	Other
Sri Lanka	18732000	3.6	148			Other
Sudan	33546000	3.9	337	15	24	Registry
Sweden	8894000	10.7	833	1361		
Switzerland	7231000	10.7	578	83	47	Registry
Thailand	61183900	3.7	1325	69	56	Registry
Tunisia†	9673600	5.5	272			Survey
Turkey	68529000	5.0	1929	100	201	Registry
Ukraine*	49093000	4.1	105	17		
United Kingdom†	58800000	7.3	6109	5582	1632	Registry
United States	285318000	13.0	14886	9801	1424	Survey
Uruguay	3361000	10.9	199			Registry
Uzbekistan	2506800	5.3	896	75	9	Survey
Venezuela	24632000	7.4	1328	517	285	Registry
Viet Nam	81314000	5.2	227	2	1	Survey
Zimbabwe*	12820650	7.3	350	15		Survey
TOTALS:	5291829030		120812	43334	11384	



C. Demographic details

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	B14. # other hereditary bleeding disorders	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B28. vWD HIV infection	B29. vWD HCV infection	B30. Cause of death: bleeding	B31. Cause of death: HIV	B32. Cause of death: liver disease	B33. Cause of death: other
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Albania	238	35	2		2	1	110			1			
Algeria	809	163	5			14	126						
Argentina	1714	226				81	662	0	26	9	2	1	3
Armenia	157	5		2									
Australia	883	187	0	804	289	85	534	4	62				
Austria	350	53	53	30		55	102	1					
Azerbaijan	792	20		190	4	0	0	0	0				
Bangladesh	208	32			2					2		1	
Belarus	480	70		800		1	400			4			
Belgium*	623	146		537	58								
Belize	11	3		3	1	0	0	0	0				
Bolivia*	10	4					2			1			
Bosnia-Herzegovina	100	10		30									
Brazil	5411	886	262	866	202	360	1461						
Bulgaria	510	59	29	56	17	9	517	0	50			1	
Canada	2221	551	0	2156	587	251	1100						
Chile*	897	129	1							2			
China	2432	278		227									
Colombia	1095	185	76	110	145	15	71	0	1	2			
Costa Rica	135	28				19	61			2	1	3	1
Croatia*	322	66		163	57	6	280	0	98			1	1
Cuba	291	63				4	106			1		1	
Cyprus	52	61		12	5	2	13						
Denmark	323	101	0	314	110	29	125	0	4	1		1	1
Dominican Republic*	175	11		9		12				2			
Ecuador						3	10			3			
Egypt	2897	650		341	652	0	12	0	2				
El Salvador	229	25		15	5	2	1			2			
Eritrea	22	1											
Estonia*	36	3		33	3	0	21	0	4				
Finland†	219	61		1589	191								

C. Demographic details



World Federation of Hemophilia Global Survey 2004

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	B14. # other hereditary bleeding disorders	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B28. vWD HIV infection	B29. vWD HCV infection	B30. Cause of death: bleeding	B31. Cause of death: HIV	B32. Cause of death: liver disease	B33. Cause of death: other
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France													
Georgia	176	31	0	12	10	0	120	0	5	2	0	0	0
Germany	4055	745		3100						3	4	1	2
Greece	702	125		514	126	77	367	2	33	0	1	0	0
Guatemala	114	9		14	72	0	26	0	0				
Honduras	117	14	24			0	3			0	0	0	0
Hungary	875	219	0	1416	551	10	301	2	101				
Iceland	56	2	0		12	0	9	0	0	0	0	0	1
India	5182	908	197			120							
Indonesia	181	24		27	2		49			4			
Iran	3394	697	346	440	328	66	3479		374	1	1	1	1
Iraq	504	120		80	96	0	374	0	48	2			
Ireland	360	185		555	285	37	157	0	11				2
Israel	340	60	21	9		27	170					1	3
Italy	3921	649	162	2248	1467	534		820					
Jamaica	101	8	0	16	12	8	36	1	1	1	1		
Japan†	3841	842	0	723	337	871	2436	7	118				
Kenya	377	46	16	7	45	39	4			2	0	0	1
Korea	1311	254	0	91	32	18	633	0	6	2			3
Latvia	87	16		39		0	60	0	18				
Lebanon	88	22		38	16	2	20	0	0				
Lithuania†	112	20	12	73	12	0	82						1
Macedonia	149	59		18		0	24	0	1	2	0	1	
Malaysia	746	128	21	266	243	12	136	0	0	0	2	0	0
Malta*	12	3			4								
Mexico	1938	289	315	32						5			
Moldova													
Mongolia	35	5	0	1		0	10						
Nepal*	67	12	60		2		3						
Netherlands	1500	100				256	1400						



C. Demographic details

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	B14. # other hereditary bleeding disorders	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B28. vWD HIV infection	B29. vWD HCV infection	B30. Cause of death: bleeding	B31. Cause of death: HIV	B32. Cause of death: liver disease	B33. Cause of death: other
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New Zealand	234	46		95	6	7	142						
Nicaragua*	119	22	23	22	8		55		3	3			
Norway†	271	91	0	710	44	9	0	0					
Pakistan	433	142		132									
Palestine	100	25		5	48					0	0	0	0
Panama	216	22	0	167	12	20	12	1	3	1	0	0	0
Peru	247	45	128	38	9	8	25	0	10	1	1		
Philippines	682	105	44	11		1	40	0	0	6			
Poland†	1918	309		670	138			6					
Portugal	488	102	45	51	10	60				3	4	0	0
Romania†	1255	159	1	214	40	19	1088	0	30	3	2		1
Russia	6358	1517		3380									
Saudi Arabia	129	38	3	42		34	81	0	3				
Senegal	137	0			2	0	0						
Serbia	421	67		193	20	45	110	4	8	0	1	1	0
Singapore*	158	20	0	48	65	0	64						
Slovak Republic	437	64	0	332	524	0	159	0	23	0	0	0	2
Slovenia†	159	16	0	63	73	16	90	0	6	1			1
South Africa	1325	254		463	206	45	53	0	0	3	0	0	8
Spain	1600	264		673	220	500	1091	32	120	4	3	8	3
Sri Lanka	111	12	15										
Sudan	259	58		13	20								
Sweden	667	166		1361		37					2	2	
Switzerland	476	102	2	83	47					7	4	3	12
Thailand	288	52		54	36	9	50	0	1	2			2
Tunisia†	235	37				10	45			13	23		
Turkey	1593	336		100	201		36			3			1
Ukraine*													
United Kingdom†	5006	1103		5582	1632	405	2829	6	218	9	8	5	48
United States	11413	3473		9801	1424	1698	4456	19	215	20	31	30	67
Uruguay	152	9				2				1	0	0	0

C. Demographic details



World Federation of Hemophilia Global Survey 2004

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	B14. # other hereditary bleeding disorders	B26. Hemophilia HIV infection	B27. Hemophilia HCV infection	B28. vWD HIV infection	B29. vWD HCV infection	B30. Cause of death: bleeding	B31. Cause of death: HIV	B32. Cause of death: liver disease	B33. Cause of death: other
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Uzbekistan	626	32		75			38		2				
Venezuela	1132	349		528	292	88	303	8	23	2	1	0	2
Viet Nam	188	39		2	1	0	43	0	0	1			
Zimbabwe*	300	50		1		9				7	2		



**D. Availability of treatment products**

Country	B18. Availability: cryoprecipitate	B19. Availability: plasma-derived concentrate	B20. Availability: recombinant concentrate	B21. Availability: DDAVP	B22. vWD availability:plasma	B23. vWD availability: cryoprecipitate	B24. vWD availability: plasma-derived concentrate	B25. vWD availability: DDAVP
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Albania	Sometimes	Rarely	Rarely	Rarely				
Algeria	Sometimes	Sometimes	Never	Rarely	Always	Sometimes	Rarely	Rarely
Argentina	Sometimes	Always	Sometimes	Sometimes	Never	Rarely	Sometimes	Sometimes
Armenia	Sometimes	Rarely	Never	Never	Always	Sometimes	Never	Never
Australia	Rarely	Sometimes	Sometimes	Sometimes	Sometimes	Rarely	Sometimes	Sometimes
Austria	Never	Sometimes	Sometimes	Rarely	Never	Never	Always	Sometimes
Azerbaijan	Rarely	Sometimes	Never	Sometimes	Always	Never	Never	Sometimes
Bangladesh	Rarely	Sometimes	Sometimes	Never				
Belarus	Sometimes	Sometimes	Never	Never	Always	Never	Never	Never
Belgium*	Never	Always	Always	Rarely	Never	Never	Always	Always
Belize		Always		Sometimes			Sometimes	Sometimes
Bolivia*	Sometimes		Rarely					
Bosnia-Herzegovina	Sometimes	Sometimes	Never	Never	Always	Sometimes	Never	Never
Brazil	Never	Always	Always	Always	Never	Never	Always	Always
Bulgaria	Never	Always	Rarely	Rarely			Always	
Canada	Never	Sometimes	Always	Sometimes			Sometimes	Sometimes
Chile*	Always	Sometimes	Rarely	Rarely	Always	Always	Rarely	Sometimes
China	Sometimes	Sometimes	Rarely	Rarely	Always	Sometimes	Sometimes	Never
Colombia		Always	Sometimes	Sometimes		Rarely	Sometimes	
Costa Rica	Never	Always	Sometimes	Sometimes		Always		Always
Croatia*	Never	Always	Always		Never	Never	Always	Sometimes
Cuba	Always	Sometimes				Always		Rarely
Cyprus		Always	Rarely				Always	
Denmark	Never	Sometimes	Always	Always	Never	Never	Always	Always
Dominican Republic*	Rarely	Sometimes	Rarely	Rarely	Always	Rarely	Sometimes	Rarely
Ecuador	Always		Rarely	Rarely		Always		Rarely
Egypt	Sometimes	Sometimes		Sometimes	Always	Sometimes	Rarely	Sometimes
El Salvador	Sometimes	Rarely	Rarely	Never		Always		
Eritrea			Always					
Estonia*	Never	Always	Never	Never	Never	Never	Always	Sometimes
Finland†	Never	Always	Always	Sometimes	Never	Never	Always	Sometimes
France	Rarely	Sometimes	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes
Georgia	Rarely	Sometimes	Rarely	Rarely	Rarely	Rarely	Sometimes	Rarely



D. Availability of treatment products



World Federation of Hemophilia Global Survey 2004

Country	B18. Availability: cryoprecipitate	B19. Availability: plasma-derived concentrate	B20. Availability: recombinant concentrate	B21. Availability: DDAVP	B22. vWD availability:plasma	B23. vWD availability: cryoprecipitate	B24. vWD availability: plasma-derived concentrate	B25. vWD availability: DDAVP
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Germany	Never	Always	Always	Rarely			Always	Always
Greece	Never	Sometimes	Sometimes	Sometimes	Never	Never	Always	Always
Guatemala	Always	Sometimes	Rarely			Always	Rarely	
Honduras		Always	Never					
Hungary	Never	Sometimes	Sometimes	Sometimes	Never	Never	Sometimes	Sometimes
Iceland	Never	Never	Always	Sometimes	Rarely	Never	Rarely	Sometimes
India	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Sometimes	Rarely
Indonesia	Always	Sometimes	Rarely	Never	Sometimes	Always	Sometimes	Never
Iran	Always	Sometimes	Rarely	Rarely	Always	Always	Sometimes	Rarely
Iraq	Sometimes	Sometimes	Never	Sometimes	Never	Always	Sometimes	Always
Ireland	Never	Rarely	Always	Sometimes	Never	Never	Sometimes	Sometimes
Israel	Rarely	Sometimes	Sometimes	Rarely	Rarely	Rarely	Sometimes	Sometimes
Italy	Never	Always	Always		Never	Never	Always	Always
Jamaica	Sometimes	Sometimes	Rarely	Rarely	Never	Always	Never	Never
Japan†	Never	Always	Always	Rarely	Never	Never	Always	Never
Kenya	Sometimes	Sometimes	Sometimes	Never	Always	Sometimes	Rarely	Never
Korea	Never	Always	Always	Rarely	Never	Never	Always	Sometimes
Latvia	Rarely	Always	Never	Always	Never	Never	Sometimes	Always
Lebanon	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Sometimes	Rarely
Lithuania†		Always	Rarely	Sometimes	Sometimes		Sometimes	Always
Macedonia	Always	Sometimes	Never	Sometimes	Never	Always	Never	Never
Malaysia		Always		Rarely			Always	Always
Malta*		Always				Always		
Mexico	Sometimes	Sometimes	Rarely	Sometimes	Sometimes	Sometimes	Sometimes	Rarely
Moldova	Always	Sometimes	Never	Sometimes	Rarely	Always	Sometimes	Sometimes
Mongolia	Always	Rarely	Rarely		Always	Always	Never	Never
Nepal*	Sometimes	Rarely	Never	Rarely				
Netherlands	Never	Never	Sometimes	Sometimes	Sometimes	Never	Never	Sometimes
New Zealand	Never	Sometimes	Sometimes	Sometimes	Never	Never	Sometimes	Sometimes
Nicaragua*	Sometimes	Sometimes	Never		Always	Sometimes	Rarely	Rarely
Norway†	Never	Always	Always	Sometimes	Never	Rarely	Always	Always
Pakistan	Sometimes	Sometimes	Sometimes		Sometimes	Sometimes	Sometimes	
Palestine	Rarely	Always	Sometimes	Rarely	Always	Rarely		Rarely



**D. Availability of treatment products**

Country	B18. Availability: cryoprecipitate	B19. Availability: plasma-derived concentrate	B20. Availability: recombinant concentrate	B21. Availability: DDAVP	B22. vWD availability:plasma	B23. vWD availability: cryoprecipitate	B24. vWD availability: plasma-derived concentrate	B25. vWD availability: DDAVP
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Panama	Rarely	Always	Rarely	Sometimes	Rarely	Sometimes	Always	Sometimes
Peru	Sometimes	Always	Never	Rarely	Never	Always	Sometimes	Sometimes
Philippines	Always	Sometimes	Rarely	Never	Always	Always	Sometimes	Rarely
Poland†		Always		Rarely		Sometimes	Sometimes	Sometimes
Portugal	Rarely	Sometimes	Sometimes	Sometimes	Never	Never	Always	Always
Romania†	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Sometimes	Rarely
Russia	Sometimes	Rarely	Never	Never	Always	Sometimes	Rarely	Never
Saudi Arabia	Never	Always	Never	Sometimes	Rarely	Rarely	Always	Sometimes
Senegal	Always	Sometimes	Sometimes	Rarely				
Serbia	Rarely	Always	Never	Sometimes	Rarely	Sometimes	Sometimes	Sometimes
Singapore*	Always	Always	Never	Sometimes	Always	Always	Always	Sometimes
Slovak Republic		Always		Rarely			Always	Rarely
Slovenia†		Always		Always			Always	Always
South Africa	Rarely	Always	Sometimes	Sometimes	Never	Sometimes	Always	Sometimes
Spain	Never	Always	Always	Always	Never	Never	Always	Always
Sri Lanka	Always	Sometimes	Rarely	Never				
Sudan	Rarely	Always	Rarely	Never	Rarely	Rarely	Always	Never
Sweden	Never	Rarely	Always	Sometimes	Never	Never	Sometimes	Sometimes
Switzerland	Never	Sometimes	Sometimes	Rarely	Never	Never	Sometimes	Sometimes
Thailand	Always	Sometimes	Rarely	Sometimes	Rarely	Sometimes	Sometimes	Sometimes
Tunisia†	Always	Never	Never		Always		Never	
Turkey	Never	Always	Rarely	Sometimes	Always	Never	Always	Sometimes
Ukraine*	Always	Sometimes	Never	Rarely	Always	Always	Sometimes	Rarely
United Kingdom†	Never	Sometimes	Sometimes	Sometimes	Never	Never		
United States	Rarely	Sometimes	Always	Sometimes	Rarely	Sometimes	Always	Always
Uruguay	Sometimes	Sometimes	Never	Rarely				
Uzbekistan	Always	Never	Rarely	Never	Always	Always	Never	Never
Venezuela	Rarely	Always	Rarely	Sometimes	Never	Rarely	Always	Sometimes
Viet Nam	Always	Never	Rarely	Never	Always	Always	Never	Never
Zimbabwe*		Sometimes						

E. Health care system



World Federation of Hemophilia Global Survey 2004

Country	Population	Health care % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique	C21. Compensation HCV	C27. Compensation HIV
Albania	3164400	3.4	1	95	Clotting screening test	no	
Algeria	30835000	3.6	14	977	Factor assay	no	no
Argentina	37488000	8.6	11	1345	Factor assay	no	yes
Armenia	3088000	7.5	0		Clotting screening test	no	no
Australia	19182000	8.3	15		Factor assay	no	yes
Austria	8132000	8	20	250	Factor assay	no	yes
Azerbaijan	8116110	0.9	1	150	Factor assay	no	no
Bangladesh	133345200	3.8	1	242	Factor assay	no	no
Belarus	9970260	5.4			Clotting screening test	no	no
Belgium*	10286000	8.7	10	1200	Factor assay		
Belize	247100	4.6	3	14	Factor assay		
Bolivia*	8515200	6.7	1	14	Clotting screening test		
Bosnia-Herzegovina	4060000	4.5			Factor assay	no	no
Brazil	172386000	8.3	27	7626	Factor assay	no	no
Bulgaria	7913000	3.9	6	500	Factor assay	no	yes
Canada	31081900	9.1	24	5515	Factor assay	yes	yes
Chile*	15402000	7.2			Factor assay		
China	1271850000	5.3			Clotting screening test		
Colombia	43035200	9.6	8	500	Factor assay	no	no
Costa Rica	3873000	6.4			Factor assay	no	
Croatia*	4380780	10	4	600	Factor assay		
Cuba	11188000	6.8	14	354	Factor assay	no	
Cyprus	11,230,000	6.8	1	64	Factor assay	no	no
Denmark	5359000	8.3	2	840	Factor assay	no	yes
Dominican Republic*	8505200	6.3			Factor assay		
Ecuador	13029000	4.1	1	120	Factor assay	no	no
Egypt	65176900	3.8	6	1500	Factor assay		
El Salvador	6400000	8.8	3	274	Factor assay	no	no
Eritrea	4389000	5.6	1	6	Clinical symptoms	no	no
Estonia*	1364000	6.1	3	39	Factor assay		
Finland†	5188000	6.6	1		Clotting screening test		
France	59725000	9.4	20		Factor assay	no	yes
Georgia	5224000	7.1	3	230	Factor assay	no	no
Germany	82333000	10.6			Factor assay	no	yes



**E. Health care system**

Country	Population	Health care % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique	C21. Compensation HCV	C27. Compensation HIV
Greece	10590870	8.3	4	3000	Factor assay		
Guatemala	12307000	4.7	1			no	yes
Honduras	6584700	6.8	2	130	Factor assay	no	no
Hungary	10187000	6.8	52		Factor assay	yes	yes
Iceland	282000	8.9	1	30	Factor assay	no	no
India	1032355000	4.9	60		Clotting screening test	no	no
Indonesia	208981100	2.7	9	850	Clotting screening test	no	no
Iran	64528200	5.5	10		Factor assay	no	no
Iraq	24700000	3.3	1	800	Factor assay	no	no
Ireland	3839000	6.7	5		Factor assay	yes	yes
Israel	6362950	10.9	3		Factor assay	no	
Italy	57948000	8.1	47	5000	Factor assay	yes	yes
Jamaica	2590000	5.5	3	109	Factor assay	no	yes
Japan†	126870000	7.8	5	1000	Factor assay		
Kenya	30735800	8.3	1	181	Clotting screening test	no	no
Korea	43343000	6	11		Factor assay	no	no
Latvia	2359000	5.9	2	110	Factor assay	no	no
Lebanon	4384700	12.4	4	110	Factor assay	no	no
Lithuania†	3482000	6	2	95	Factor assay		
Macedonia	2035000	6	1	200	Factor assay	no	no
Malaysia	23802400	2.5	36		Factor assay	no	no
Malta*	395000	8.8			Not known		
Mexico	99419700	5.4	4	1000	Clotting screening test	no	no
Moldova	4270000	3.5			Factor assay	no	no
Mongolia	2421400	6.6	3	32	Factor assay	no	no
Nepal*	23584700	4.2	1	139	Factor assay		
Netherlands	16039000	8.1	16	1600	Factor assay	no	yes
New Zealand	3849000	8	6		Factor assay	yes	yes
Nicaragua*	5205000	4.4	1	196	Clotting screening test		
Norway†	4513000	7.8	1		Factor assay		
Pakistan	141450100	4.1			Factor assay	no	no
Palestine	1300000		7	125	Factor assay	no	no
Panama	2897000	7.6	2	41	Factor assay		
Peru	27148000	4.7	7	339	Clotting screening test	no	no
Philippines	78317000	3.4	1	62	Factor assay	no	no



E. Health care system



World Federation of Hemophilia Global Survey 2004

Country	Population	Health care % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique	C21. Compensation HCV	C27. Compensation HIV
Poland†	38641000	6	32		Factor assay		
Portugal	10024000	8.2	7		Factor assay	no	yes
Romania†	22408000	2.9	7		Clotting screening test		
Russia	144752000	5.3	4	1500	Factor assay	no	no
Saudi Arabia	21408470	5.3	1	170	Factor assay	no	no
Senegal	10651000	5.6	1	108	Factor assay		no
Serbia	10,048,000	4.6	8	350	Factor assay	no	yes
Singapore*	4131000	3.5	3		Factor assay		
Slovak Republic	5404000	5.9	44	380	Factor assay	no	
Slovenia†	19920000	8.6	1	311	Factor assay		
South Africa	43240000	8.8	11	800	Factor assay	no	no
Spain	41117000	7.7	34	2300	Factor assay	yes	yes
Sri Lanka	18732000	3.6			Clinical symptoms	no	
Sudan	33546000	3.9	1		Factor assay		
Sweden	8894000	10.7	3		Factor assay	yes	yes
Switzerland	7231000	10.7	18	709	Factor assay	no	yes
Thailand	61183900	3.7	26	1325	Factor assay	no	no
Tunisia†	9673600	5.5	3		Factor assay		
Turkey	68529000	5	19	2000	Factor assay	no	no
Ukraine*	49093000	4.1			Clinical symptoms		
United Kingdom†	58800000	7.3	23		Factor assay		
United States	285318000	13	142	26248	Factor assay	no	yes
Uruguay	3361000	10.9	14	179	Factor assay	no	no
Uzbekistan	2506800	5.3	1	320	Clinical symptoms	no	no
Venezuela	24632000	7.4	12		Factor assay	no	no
Viet Nam	81314000	5.2	1	230	Factor assay	no	no
Zimbabwe*	12820650	7.3			Factor assay		



**F. 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	850000	90000			20000		760000	
Algeria								
Argentina								
Armenia	30000						30000	
Australia	84200000		48100000		36100000			
Austria								
Azerbaijan							500000	
Bangladesh	313903	41570	261380	0	52523	41570	105903	41570
Belarus	2000000	500000	2000000	500000				
Belgium*								
Belize	70000	120000					20000	50000
Bolivia*								
Bosnia-Herzegovina	300000	100000	300000	100000				
Brazil	160000000	27000000	160000000	27000000		450000		
Bulgaria	8700000	450000	8500000	450000	200000			
Canada	125000000	31000000	1325000	4300000	123675000	26700000		
Chile*								
China								
Colombia	22300000	2500000	22000000	1000000	3000000	1500000		
Costa Rica								
Croatia*								
Cuba	801150	10000			801150	10000	801150	10000
Cyprus								
Denmark	215000000	3500000	1000000		19500000	3500000		
Dominican Republic*								
Ecuador								
Egypt								
El Salvador								
Eritrea	981804							
Estonia*								
Finland†								
France	400000000	61000000	80000000	29000000	320000000	32000000		
Georgia	969700	100000	0	25000				



F. Use of factor concentrates



World Federation of Hemophilia Global Survey 2004

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
Germany								
Greece	17817383	2927290	5006917	155612	12810466	2771678		
Guatemala								
Honduras	1212500							
Hungary	51300000	4500000	49800000	4500000	1500000			
Iceland	2710000	19000	0	0	2710000	19000		
India	9941556	1382346					4649941	536346
Indonesia								
Iran	60000000	15000000	60000000	15000000				
Iraq	400500	89200						
Ireland	20805066	10599228			20805066	10599228		
Israel								
Italy								
Jamaica								
Japan†								
Kenya	910741	111500					910741	111500
Korea	54274025	9104257	54149225	1639623	124800	7464626		
Latvia	1897680	288495	1897680	288495			51800	
Lebanon	2348420	729600	1408000	729600			868420	
Lithuania†								
Macedonia	900000	50000	900000	50000			500000	
Malaysia	9810000	5999000						
Malta*								
Mexico	30000000	6600000	30000000	6000000				
Moldova	108000						108000	
Mongolia	496210				496210		496210	
Nepal*								
Netherlands								
New Zealand	16800000	3550000	8900000	2900000	7900000	650000		
Nicaragua*								
Norway†								
Pakistan								



**F. 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
Palestine	1470500	42480						
Panama	78500	31950	78500	30600	0	1350		
Peru	4500000	1000000	4500000	1000000				
Philippines	915697		900000					
Poland†								
Portugal	29769000	4770000	14873000	4420000	14896000	350000		
Romania†								
Russia	25000000	7000000	25000000	7000000				
Saudi Arabia								
Senegal								
Serbia	2238000	200400	2238000	200400				
Singapore*								
Slovak Republic	15900000	1300000	15900000	1300000				
Slovenia†								
South Africa	23000000	3000000	23000000	3000000				
Spain	88000000	16000000	36000000	11000000	52000000	5000000		
Sri Lanka								
Sudan	1200000	75000						
Sweden								
Switzerland	23369000	4388400	9112750	3967400	14256250	421000		
Thailand								
Tunisia†								
Turkey	42000000	8000000						
Ukraine*								
United Kingdom†								
United States								
Uruguay	4145250	430000	1000000					
Uzbekistan							325575	
Venezuela	12025250	3079800	12025250	3079800				
Viet Nam							300000	
Zimbabwe*								

G. Products used

D4. Factor VIII Concentrates		
Brand Name	Manufacturer	Reported Used In
Aafact	Sanquin, CLB	India; Netherlands
AHF (High Purity)	CSL Ltd.	Australia; Israel; Malaysia; New Zealand
Alphanate	Alpha	Brazil; India; Italy; Malaysia; New Zealand; Pakistan; Peru; Philippines; Thailand; United States
Beriate P = Beriate HS	Aventis Behring	Argentina; Austria; Brazil; Italy; Kenya; Mexico; Serbia; Slovak Republic; Spain; Switzerland; Turkey
Biostate (Factor VIII)	CSL Ltd.	Australia
Emoclot D.I.	Kedrion	Argentina; Brazil; India; Iraq; Italy; Macedonia; Portugal; Russia; Turkey
FACTANE	LFB	France; India; Iraq; Senegal; Turkey
Factor 8 Y	Bio Products Laboratory	Brazil; Colombia; Greece; India; Iraq; Israel; Latvia; Sudan; Turkey
Fanhdi	Grifols	Argentina; Brazil; Germany; Ireland; Italy; Mexico; Peru; Slovak Republic; Spain; Turkey; Venezuela
GreenEight	Greencross PD	Korea; Uruguay
GreenMono	Greencross PD	Korea
Haemate P = Haemate HS	Aventis Behring	Argentina; Austria; Bosnia and Herzegovina; Denmark; Germany; Greece; Hungary; Iceland; India; Israel; Italy; Lebanon; Netherlands; Palestine; Portugal; Serbia; Slovak Republic; Spain; Sweden; Switzerland; Turkey
Haemoctin SDH (=Faktor VIII Intersero)	Intersero	Austria; Bosnia and Herzegovina; Colombia; Germany; Hungary; India; Iran; Latvia; Panama; Russia
Haemosolvate Factor VIII	Natal Bioproducts Institute	South Africa
Helixate FS = Helixate NexGen	Aventis Behring	Austria; Denmark; France; Greece; Iceland; India; Ireland; Italy; Kenya; Netherlands; Portugal; Spain; Sweden; Switzerland; United States
Hemofil M AHF	Baxter	Argentina; Brazil; Canada; Colombia; Ecuador; El Salvador; France; Greece; Guatemala; Hungary; India; Israel; Italy; Kenya; Latvia; Malaysia; Mexico; Panama; Peru; Philippines; Portugal; Russia; Slovak Republic; Spain; Thailand; Turkey; United States; Venezuela
HEMORAAS, SD plus H	Shanghai RAAS	Azerbaijan; China; Georgia; Pakistan
HEMORAAS-HP, SD plus H	Shanghai RAAS	Pakistan
HEMORAAS-IP, SD plus H	Shanghai RAAS	Pakistan
Humate P	Aventis Behring	Canada; India; Israel; United States
Immunate	Baxter Bioscience	Algeria; Austria; Bulgaria; Colombia; Georgia; Germany; Hungary; India; Israel; Italy; Mexico; Netherlands; Russia; Serbia; Slovak Republic; Sweden; Switzerland; Turkey; Venezuela

**G. Products used**

Koate DVI	Bayer	Argentina; Brazil; Bulgaria; Colombia; El Salvador; Georgia; Guatemala; Hungary; India; Indonesia; Iran; Israel; Latvia; Malaysia; Mexico; Pakistan; Panama; Philippines; Russia; Turkey; United States; Uruguay
Kogenate FS = Kogenate Bayer (in EU)	Bayer	Austria; Azerbaijan; Bulgaria; Canada; Denmark; Eritrea; France; Germany; Greece; Hungary; India; Ireland; Israel; Kenya; Mexico; Netherlands, New Zealand; Palestine; Portugal; Senegal; Spain; Sweden; Switzerland; United States; Uzbekistan
Monarc-M	American Red Cross	Argentina; Belize; Brazil; Germany; India; Israel; Panama; Turkey; United States; Uruguay; Venezuela
Monoclate P	Aventis Behring	France; Germany; India; Israel; Kenya; Korea; Sweden; United States
Octanate	Octapharma	Austria; Brazil; Germany; Hungary; India; Mexico; Peru; Russia; Slovak Republic; Spain; Thailand; Turkey; Venezuela
Octonativ-M	Octapharma	Armenia; El Salvador; Germany; Iran; Uruguay
Profilate	Grifols	Germany; Malaysia
Recombinate	Baxter Bioscience	Argentina; Australia; Canada; Colombia; Cuba; Denmark; Eritrea; France; Germany; Greece; Iceland; India; Ireland; Israel; Italy; Korea; Netherlands; New Zealand; Portugal; Spain; Sweden; Switzerland; United States
ReFacto	Wyeth	Austria; Azerbaijan; Cuba; Denmark; Ecuador; Eritrea; France; Germany; Greece; Israel; Italy; Kenya; Netherlands; New Zealand; Palestine; Portugal; Senegal; Spain; Sudan; Sweden; Switzerland; United States; Uzbekistan
Replenate	Bio Products Laboratory	India; Israel; Macedonia
D5. Factor IX Concentrates		
Brand Name	Manufacturer	Reported Used In
Aimafix D.I.	Kedrion	Argentina; Georgia; India; Iran; Italy; Macedonia; Russia; Turkey; Venezuela
Alphanine SD	Alpha	Brazil; India; Israel; Italy; Malaysia; Pakistan; Peru; Thailand; United States
BeneFIX	Wyeth	Argentina; Australia; Brazil; Canada; Colombia; Denmark; India; Israel; Korea; New Zealand; Palestine; Spain; Sweden; Switzerland; United States
BeneFIX	Baxter SA	Austria; France; Germany; Greece; Iceland; Ireland; Italy; Netherlands; Palestine; Portugal
Berinin-P = Berinin HS	Aventis Behring	Argentina; Germany; Lebanon; Mexico; Serbia; Switzerland; Turkey
BETAFACT	LFB	France; Greece; Iraq; Palestine; Turkey
Faktor IX SDN	Biotest	Austria; Brazil
Immunine	Baxter	Algeria; Austria; Brazil; Bulgaria; Canada; Colombia; Georgia; Germany; Hungary; India; Italy; Latvia; Mexico; Peru; Russia; Slovak Republic; Spain; Sweden; Switzerland; Turkey
Mono FIX-VF	CSL	Australia; New Zealand



G. Products used

Mononine	Aventis Behring	Austria; Canada; France; Germany; India; Israel; Italy; Kenya; Netherlands; Spain; Sweden; United States
Nanotiv	Octapharma	Iran; Sweden
Octanine F	Octapharma	Cuba; Israel; Portugal; Russia; Slovak Republic; Thailand; Turkey; Uruguay
Octanyne	Octapharma	Austria; Brazil; El Salvador; Israel; Mexico; Peru; Turkey
Replenine – VF	Bio Products Laboratory	Brazil; Iraq; Latvia; Mexico; Turkey
D6. Prothrombin Complex Concentrates		
Brand Name	Manufacturer	Reported Used In
Autoplex-T	NABI, Boca Raton, Florida, USA	India; Israel; United States
Bebulin VH	Baxter	Austria; India; United States
Beriplex P/N	Aventis Behring	Argentina; Austria; Germany; Hungary; Ireland; Sweden
Facnyne	Greencross PD	Korea
Faktor IX HS	Aventis Behring	Spain
FEIBA VH	Baxter	Argentina; Austria; Brazil; Canada; Colombia; Denmark; France; Georgia; Germany; Greece; Hungary; India; Iran; Ireland; Israel; Italy; Korea; Latvia; Mexico; New Zealand; Portugal; Russia; Slovak Republic; South Africa; Spain; Sweden; Switzerland; Turkey; United States; Venezuela
Haemosolvex Factor IX	Natal Bioproducts	South Africa
KASKADIL	LFB	Brazil; Costa Rica; France; Senegal
Profilnine SD	Alpha	Brazil; India; Malaysia; Philippines; Thailand; United States
Proplex-T	Baxter	Ecuador; India; Israel; Panama; Peru; United States; Venezuela
Prothoraas SD plus Nanofil	Shanghai RAAS	China
Prothrombinex- HT	CSL	Australia; New Zealand
Prothrombinkomplex NDS	German Red Cross BSD NSTOB	Germany
Prothromplex-T	Baxter	Argentina; Brazil; Canada; Colombia; Hungary; Iceland; India; Ireland; Italy; Panama; Peru; Sweden; Switzerland; Venezuela
UMAN Complex D.I.	Kedrion	Italy; Russia

**G. Products used****D7. Other Products**

Brand Name	Manufacturer	Reported Used In
Clottagen (fibrinogen)	LFB	France; Iran
FACTEUR VII	LFB	France; Greece; Israel
Facteur von Willebrand	LFB	France; Turkey
Factor VII	Bio Products Laboratory	Australia
Factor VII	Baxter	Canada; Denmark; Greece; Slovak Republic; Switzerland; Venezuela
Factor XI	Bio Products Laboratory	Australia; Canada
Fibrinogen	SNBTS	Korea
Fibrinogen HT	Benesis	Israel
Fibrogammin HS = Fibrogammin P (Factor XIII)	Aventis Behring	Canada; Denmark; France; Germany; Greece; Ireland; Sweden; Switzerland
Haemocompletan HS = Haemocompletan P (fibrinogen)	Aventis Behring	Canada; France; Germany; Hungary; Ireland; Italy; Lebanon; Slovak Republic; Switzerland
HEMOLEVEN (Factor XI)	LFB	France; Israel; Spain
NovoSeven (Factor VIIa) = Niastase (Canada)	NovoNordisk	Argentina; Australia; Austria; Brazil; Canada; Colombia; Denmark; France; Greece; Hungary; Iceland; India; Iran; Iraq; Ireland; Israel; Italy; Kenya; Korea; Lebanon; Macedonia; Mexico; Netherlands; New Zealand; Peru; Philippines; Portugal; Russia; Serbia; Slovak Republic; South Africa; Spain; Sweden; Switzerland; Thailand; Turkey; United States
WILFACTIN	LFB	France



**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		<input type="checkbox"/>

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



**Sample survey**

B5. How much of your country is covered by this number?	<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	
B14. Other hereditary bleeding disorders	

Number of identified people with hemophilia by diagnosis of severity

Type of hemophilia	Mild	Moderate	Severe	No Data
B15. Hemophilia A				<input type="checkbox"/>
B16. 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, 2003)

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other 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"/>



Sample survey

Hepatitis C		
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?	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 persons with vWD using home care?	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?

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

D4. Factor VIII 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.)

Local currency: _____

Used	Brand Name	Manufacturer	Price per IU
<input type="checkbox"/>	Aafact	Sanquin, CLB	
<input type="checkbox"/>	AHF (High Purity)	CSL Ltd.	
<input type="checkbox"/>	Alphanate	Alpha	
<input type="checkbox"/>	Amofil	Finnish Red Cross BTS	
<input type="checkbox"/>	Beriate P = Beriate HS	Aventis Behring	
<input type="checkbox"/>	Biostate (Factor VIII)	CSL Ltd.	



**Sample survey**

<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	Bio Products Laboratory	
<input type="checkbox"/>	Fanhdi	Grifols	
<input type="checkbox"/>	GreenEight	Greencross PD	
<input type="checkbox"/>	GreenMono	Greencross PD	
<input type="checkbox"/>	Haemate P = Haemate HS	Aventis Behring	
<input type="checkbox"/>	Haemoctin SDH (=Faktor VIII Intersero)	Intersero	
<input type="checkbox"/>	Haemosolvate Factor VIII	Natal Bioproducts Institute	
<input type="checkbox"/>	Helixate FS = Helixate NexGen	Aventis Behring	
<input type="checkbox"/>	Hemofil M AHF	Baxter	
<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	Aventis Behring	
<input type="checkbox"/>	HYATE:C	IPSEN, Inc.	
<input type="checkbox"/>	Immunate	Baxter Bioscience	
<input type="checkbox"/>	Koate DVI	Bayer	
<input type="checkbox"/>	Kogenate FS = Kogenate Bayer (in EU)	Bayer	
<input type="checkbox"/>	Liberate HT	SNBTS	
<input type="checkbox"/>	Monarc-M	American Red Cross	
<input type="checkbox"/>	Monoclote P	Aventis Behring	
<input type="checkbox"/>	Octanate	Octapharma	
<input type="checkbox"/>	Octonativ-M	Octapharma	
<input type="checkbox"/>	Profilate	Grifols	
<input type="checkbox"/>	Recombinate	Baxter Bioscience	
<input type="checkbox"/>	ReFacto	Wyeth	
<input type="checkbox"/>	Replenate	Bio Products Laboratory	

D5. 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 D.I.	Kedrion	
<input type="checkbox"/>	Alphanine SD	Alpha	
<input type="checkbox"/>	Bemofil	Finnish Red Cross BTS	
<input type="checkbox"/>	BeneFIX	Wyeth	
<input type="checkbox"/>	BeneFIX	Baxter SA	
<input type="checkbox"/>	Berinin-P = Berinin HS	Aventis Behring	
<input type="checkbox"/>	BETAFACT	LFB	
<input type="checkbox"/>	Christmassin-M	Benesis	



<input type="checkbox"/>	Faktor IX SDN	Biotest	
<input type="checkbox"/>	Hemo-B-RAAS	Shanghai RAAS	
<input type="checkbox"/>	HIP FIX	SNBTS	
<input type="checkbox"/>	Immunine	Baxter	
<input type="checkbox"/>	Mono FIX-VF	CSL	
<input type="checkbox"/>	Mononine	Aventis Behring	
<input type="checkbox"/>	Nanotiv	Octapharma	
<input type="checkbox"/>	Nonafact	Sanquin	
<input type="checkbox"/>	Novact M	Kaketsuken	
<input type="checkbox"/>	NOVIX	Grifols	
<input type="checkbox"/>	Octanine F	Octapharma	
<input type="checkbox"/>	Octanyne	Octapharma	
<input type="checkbox"/>	Replenine – VF	Bio Products Laboratory	

D6. 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"/>	Autoplex-T	NABI, Boca Raton, Florida, USA	
<input type="checkbox"/>	Bebulin VH	Baxter	
<input type="checkbox"/>	Beriplex P/N	Aventis Behring	
<input type="checkbox"/>	Cofact (= PPSB in Belgium)	Sanquin	
<input type="checkbox"/>	Facnyne	Greencross PD	
<input type="checkbox"/>	Faktor IX HS	Aventis Behring	
<input type="checkbox"/>	FEIBA VH	Baxter	
<input type="checkbox"/>	Haemosolvex Factor IX	Natal Bioproducts	
<input type="checkbox"/>	HT DEFIX	SNBTS	
<input type="checkbox"/>	KASKADIL	LFB	
<input type="checkbox"/>	Profilnine SD	Alpha	
<input type="checkbox"/>	Proplex-T	Baxter	
<input type="checkbox"/>	Prothoraas SD plus Nanofil	Shanghai RAAS	
<input type="checkbox"/>	Prothrombinex- HT	CSL	
<input type="checkbox"/>	Prothrombinkomplex NDS	German Red Cross BSD NSTOB	
<input type="checkbox"/>	Prothromplex-T	Baxter	
<input type="checkbox"/>	UMAN Complex D.I.	Kedrion	

D7. 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"/>	FACTEUR VII	LFB	
<input type="checkbox"/>	Facteur von Willebrand	LFB	
<input type="checkbox"/>	Factor VII	Bio Products Laboratory	
<input type="checkbox"/>	Factor VII	Baxter	



Sample survey

<input type="checkbox"/>	Factor XI	Bio Products Laboratory	
<input type="checkbox"/>	Fibrinogen	SNBTS	
<input type="checkbox"/>	Fibrinogen HT	Benesis	
<input type="checkbox"/>	Fibrogammin HS = Fibrogammin P (Factor XIII)	Aventis Behring	
<input type="checkbox"/>	FIBRORAAS (fibrinogen)	Shanghai RAAS	
<input type="checkbox"/>	Haemocomplettan HS = Haemocomplettan P (fibrinogen)	Aventis Behring	
<input type="checkbox"/>	HEMOLEVEN (Factor XI)	LFB	
<input type="checkbox"/>	NovoSeven (Factor VIIa) = Niastase (Canada)	NovoNordisk	
<input type="checkbox"/>	Thrombin	SNBTS	
<input type="checkbox"/>	WILFACTIN	LFB	

Suggestions for next year's survey:

Completed by:

Date:

Contact info:

Please return to: Mark Brooker, WFH Public Policy Officer **Email:** mbrooker@wfh.org

Fax: (514-875-8916)

or return by mail to:

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



Glossary of terms

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.

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.

HCV: Hepatitis C virus.

Home care: The patient administers his/her 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.

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.