

# **World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2003**

*Report on the Annual Global Survey 2003* 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 2003

*Report on the Annual Global Survey 2003* 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 2003 survey is the fifth WFH survey. It gathers data for the years 2002 and 2003. The survey includes data on more than 160,000 people with hemophilia and von Willebrand disease in 86 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 prices of treatment products. It includes only those countries where the national hemophilia organization provided information. When prices were given in a local currency, they were converted by the WFH using exchange rates provided by OANDA.com. **Reported prices were not confirmed by independent sources.**



## 2003 WFH Global Survey Summary

### Demographics

Number of countries in this survey: **86**

Percentage of world population covered by 2003 survey: **81%**

Number of people identified with hemophilia A and B (question B1) : **105,971**

Number of people identified with vWD (question B2): **41,323**

Number of people identified with other bleeding disorders (question B3): **16,196**

Total number of people with bleeding disorders identified: **164,077**

Number of people with hemophilia A (question B10): **79,408**

Number of people with hemophilia B (question B11): **16,196**

Number of countries using national registries to report these numbers: **39**

Reported number of PWH infected with HIV: **6,214** (8% of PWH in reporting countries)

Reported number of PWH infected with HCV: **26,969** (36% of PWH in reporting countries)

### Factor usage

*(57 countries reporting)*

Per capita factor VIII usage (GNP above US\$10,000): **3.22 IU**

Per capita factor IX usage (GNP above US\$10,000): **0.38 IU**

Per capita factor VIII usage (GNP between US\$2000-US\$10,000): **0.78 IU**

Per capita factor IX usage (GNP between US\$2000-US\$10,000): **0.10 IU**

Per capita factor VIII usage (GNP below US\$2,000): **0.07 IU**

Per capita factor IX usage (GNP below US\$2,000): **0.01 IU**

Total reported consumption of factor VIII concentrates: **1,787,574,031 IU**

Total reported consumption of factor IX concentrates: **232,965,844 IU**

Ratio of reported plasma-derived factor concentrate vs recombinant factor concentrate: **58:42**

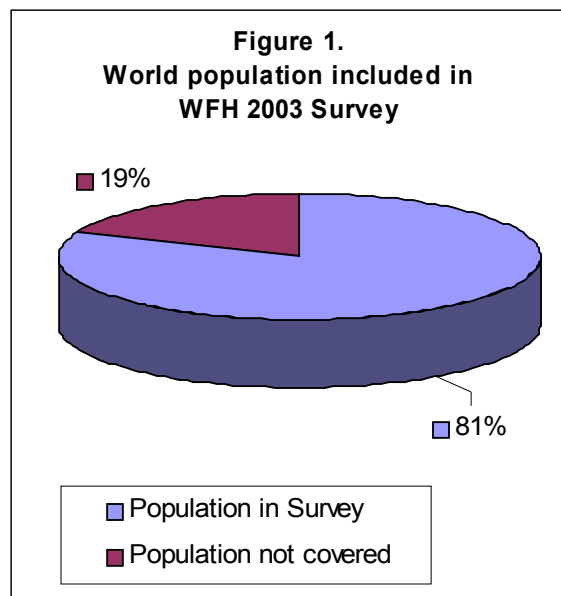


## Countries included in the 2003 WFH Global Survey

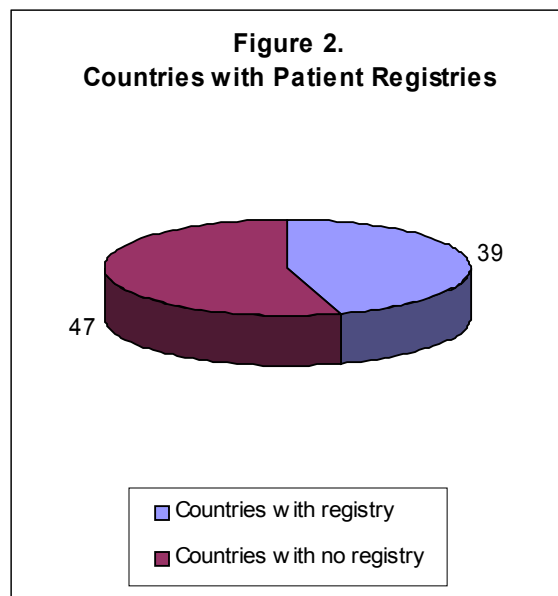
1. Albania
2. Algeria\*
3. Argentina
4. Armenia
5. Australia
6. Austria
7. Azerbaijan
8. Bangladesh
9. Belarus
10. Belgium\*
11. Belize
12. Bolivia\*
13. Bosnia-Herzegovina
14. Brazil
15. Bulgaria
16. Canada\*
17. Chile\*
18. China\*
19. Colombia
20. Costa Rica
21. Croatia\*
22. Cuba
23. Cyprus
24. Denmark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

Data collected in 2003, except \* collected in 2002

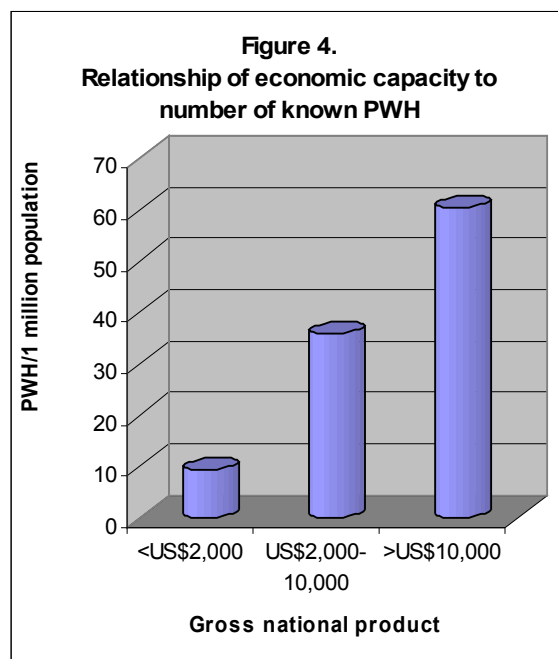
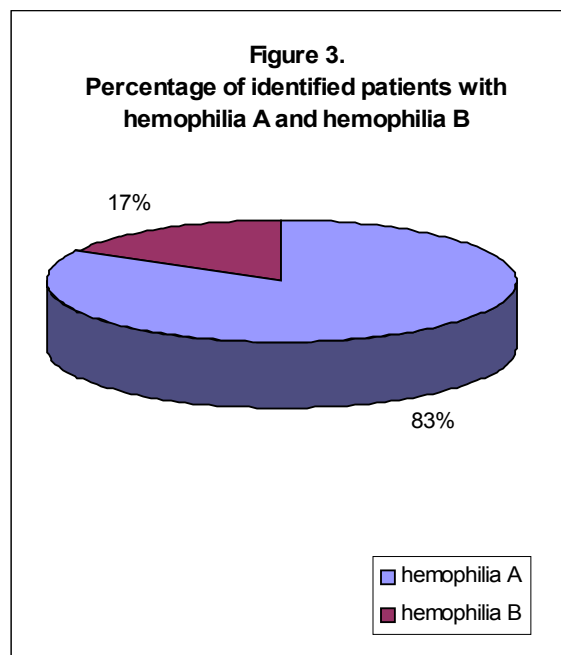




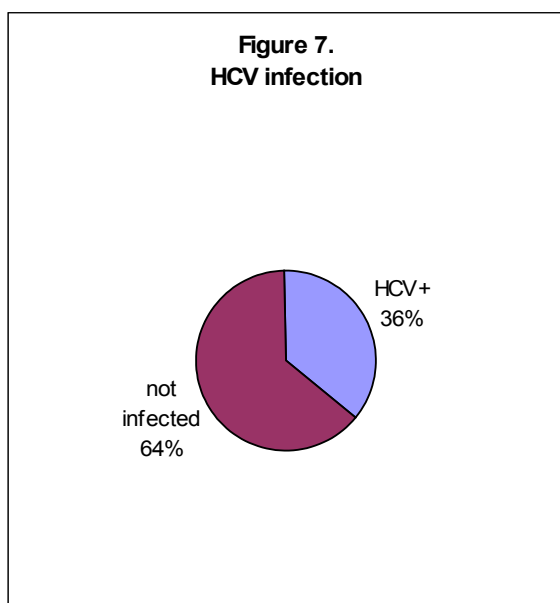
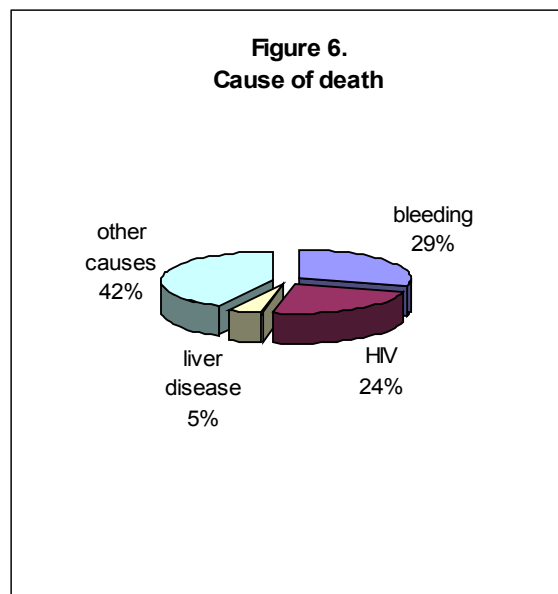
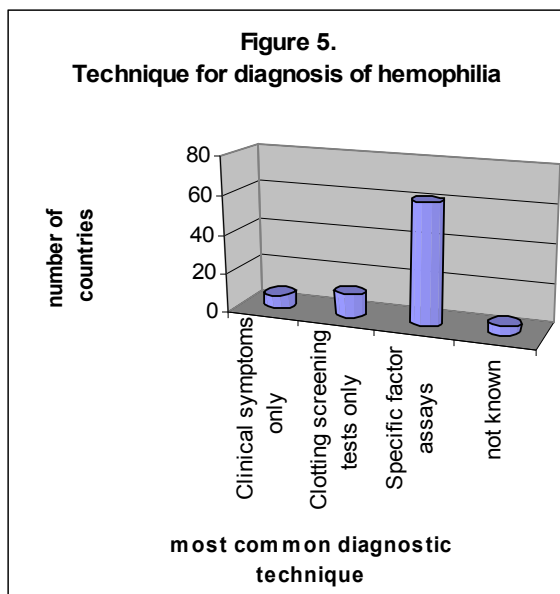
The world population is approximately 6.2 billion. Countries with a total of population of 5 billion are included in this survey.



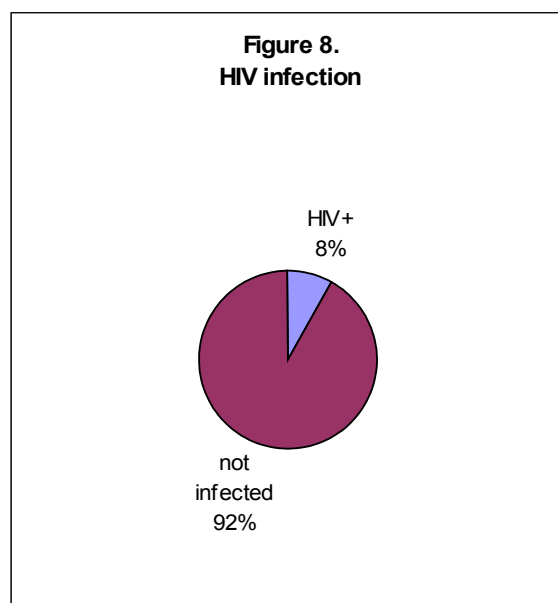
Of the 86 countries in this survey, 39 used a patient registry to report the number of people with bleeding disorders.



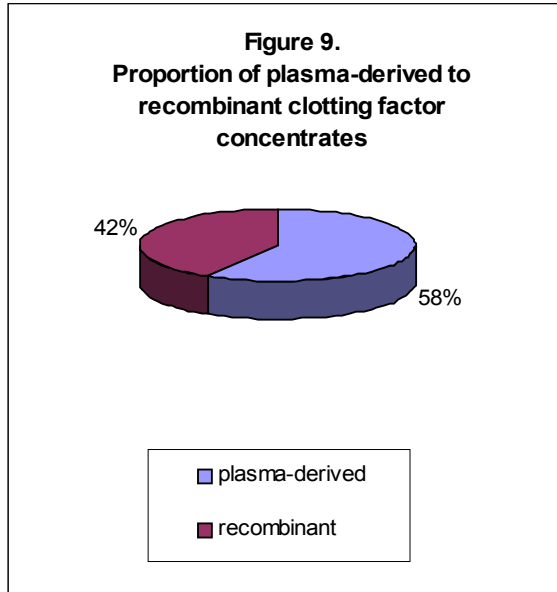




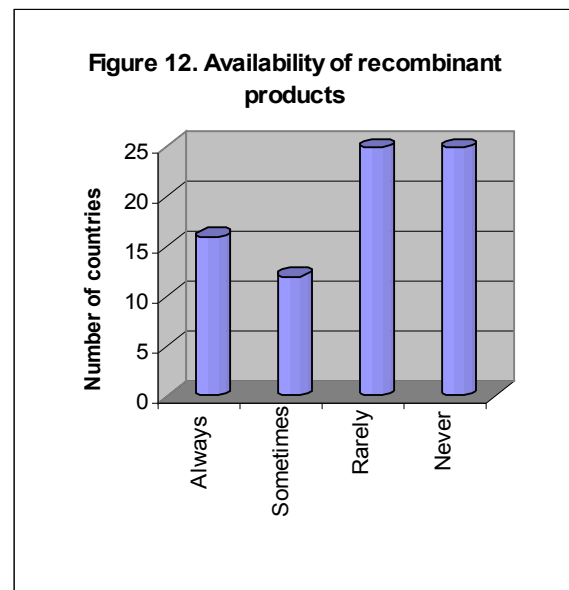
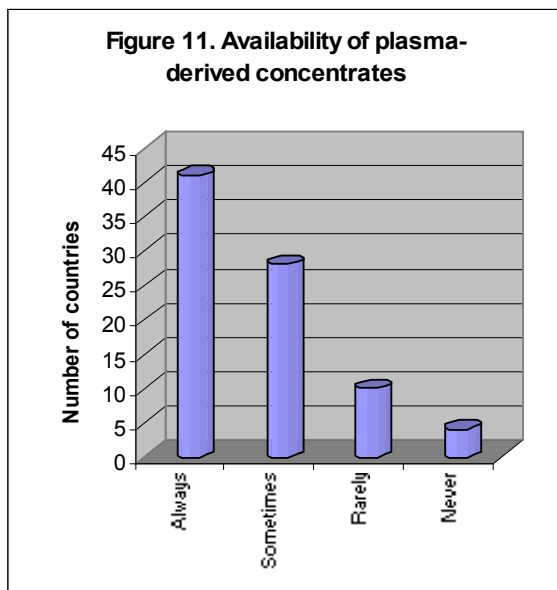
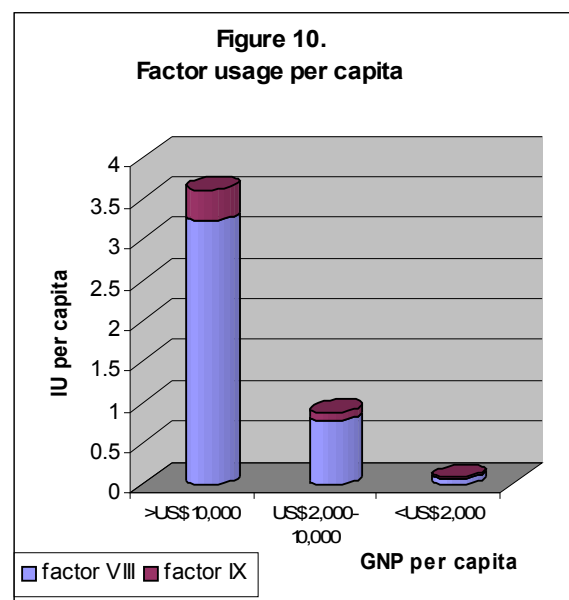
This figure uses data only from countries that reported both the total number of people with hemophilia and the number of people infected.



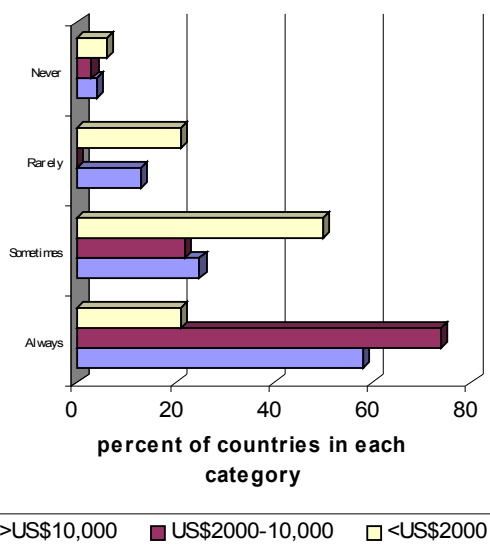
This figure uses data only from countries that reported both the total number of people with hemophilia and the number of people infected.



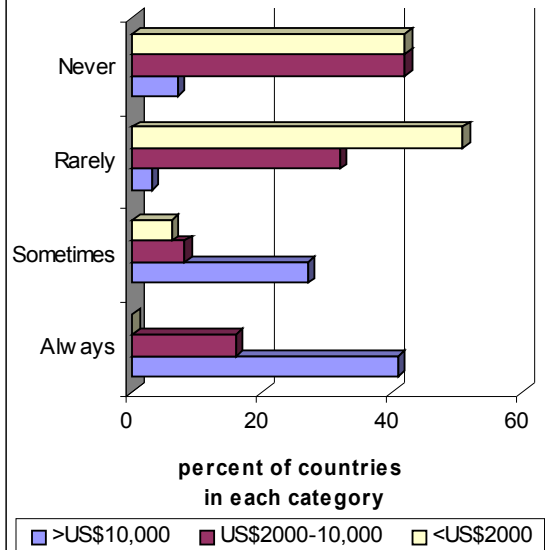
This figure uses data only from countries that reported on the breakdown between plasma-derived and recombinant consumption.



**Figure 13. Availability of plasma-derived products and economic capacity**



**Figure 14. Availability of recombinant products and economic capacity**



## 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
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### Africa

Kenya*	30,735,800	8.3	432	13	5	
South Africa	43,240,000	8.8	1463	392	204	Registry
Zimbabwe*	12,820,650	7.3	350	15		Survey

### Americas

Argentina	37,488,000	8.6	1836			Registry
Belize	247,100	4.6	10			Registry
Bolivia*	8,515,200	6.7	14			
Brazil	172,386,000	8.3	6297	866	463	Registry
Canada*	31,081,900	9.1	2419	758		Registry
Chile*	15,402,000	7.2	1027			Registry
Colombia	43,035,200	9.6	1295	88	110	Survey
Costa Rica	3,873,000	6.4	163			Survey
Cuba	11,188,000	6.8	328			Registry
Dominican Republic*	8,505,200	6.3	198	9		Survey
El Salvador	6,400,000	8.8	228	17	9	Registry
Honduras	6,584,700	6.8	80			Registry
Jamaica	2,590,000	5.5	108	16	12	Registry
Mexico	99,419,700	5.4	2233	22		Registry
Nicaragua*	5,205,000	4.4	164	22	8	Survey
Panama	2,897,000	7.6	227	133	10	Survey
United States	285,318,000	13	14,460	8622	4266	Survey
Uruguay	3,361,000	10.9	185			Registry
Venezuela	24,632,000	7.4	1198	452	237	Registry

### Eastern Mediterranean

Algeria*	30,835,000	3.6	969			Survey
Egypt*	65,176,900	3.8	4141	325	633	Survey
Iran	64,528,200	5.5	3363	523	1006	Survey
Lebanon*	4,384,700	12.4	192	2		
Saudi Arabia	21,408,470	5.3	158	33		Other
Tunisia	9,673,600	5.5	272			Survey

### Europe

Albania	3,164,400	3.4	260			Registry
Armenia	3,088,000	7.5	162	2		Survey

## B. Population statistics



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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
Austria	8,132,000	8	403			Survey
Azerbaijan	8,116,110	0.9	500			Registry
Belarus	9,970,260	5.7	545	800		Other
Belgium*	10,286,000	8.7	762	553	49	Survey
Bosnia Herzegovina	4,060,000	4.5	140	30		
Bulgaria	7,913,000	3.9	598	56	17	Registry
Croatia	4,380,780	10	388	163	57	Registry
Cyprus	11,230,000	6.8	64	2		Other
Denmark	5,359,000	8.3	417	291	105	Survey
Estonia*	1,364,000	6.1	39	33	3	
Finland	5,188,000	6.6	280	1589	191	Registry
Georgia	5,224,000	7.1	351	3	3	Registry
Germany	82,333,000	10.6	4723	3036		Registry
Greece	10,590,870	8.3	804	480	157	Survey
Hungary*	10,187,000	6.8	1227	1003	375	Survey
Iceland	282,000	8.9	59	107	12	Registry
Ireland	3,839,000	6.7	495	468	364	Other
Israel	6,362,950	10.9	381			Registry
Italy*	57,948,000	8.1	5000	3000	2500	
Latvia	2,359,000	5.9	100	37		Registry
Lithuania	3,482,000	6	132	73	20	Survey
Macedonia*	2,035,000	6	248	23		
Malta*	395,000	8.8	15		4	
Moldova	4,270,000	3.5	194	15	5	Survey
Netherlands	16,039,000	8.1	1500			Survey
Norway	4,513,000	7.8	362	710	44	Registry
Poland	38,641,000	6	2227	670	138	Registry
Portugal	10,024,000	8.2	614	43	10	Other
Romania	22,408,000	2.9	1414	214	40	Survey
Russia	144,752,000	5.3	9000	3650		Survey
Serbia & Montenegro	10,651,000	5.6	475	185	17	Registry
Slovak Republic	5,404,000	5.9	501	321	483	Registry
Slovenia	19,920,000	8.6	175	63	73	Registry
Spain	41,117,000	7.7	2384	1899	321	Survey
Sweden	8,894,000	10.7	830	1327		Survey
Switzerland	7,231,000	10.7	532	86	52	Registry
Turkey	68,529,000	5	1264	92	40	Registry
Ukraine*	49,093,000	4.1	105	17		

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)

(Countries divided into regions based on WHO system)



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**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
United Kingdom	58,800,000	7.3	6109	5582	1632	Registry
Uzbekistan	2,506,800	5.3	853	58	5	Survey

**South East Asia**

Bangladesh	133,345,200	3.8	211		1	Registry
China*	1,271,850,000	5.3				
India	1,032,355,000	4.9	3459	25	2117	Registry
Indonesia	208,981,100	2.7	150	27	2	Registry
Pakistan	141,450,100	4.1	387	49	17	Registry
Sri Lanka*	18,732,000	3.6	76			Registry
Thailand	61,183,900	3.7	1325	69		

**Western Pacific**

Australia	19,182,000	8.3	1443	1082	317	Registry
Japan	126,870,000	7.8	4683	723	337	Other
Korea*	43,343,000	6	1472	66	20	Survey
Malaysia	23,802,400	2.5	849	234	225	Registry
Mongolia	2,421,400	6.6	33			Survey
Nepal*	23,584,700	4.2	139		2	Survey
New Zealand	3,849,000	8	440			Survey
Philippines	78,317,000	3.4	684	11		Registry
Singapore*	4,131,000	3.5	178	48	65	Survey

<b>TOTALS:</b>	<b>5,024,412,290</b>		<b>105,971</b>	<b>41,323</b>	<b>16,783</b>	
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## C. Demographic details



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Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	disorders 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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### Africa

Kenya*	391	41	7	13	12	7	0						
South Africa	1230	233		392	204	45	54				1		1
Zimbabwe*	300	50		1		9				7	2		

### Americas

Argentina	1656	180		309		83	641	0	26	5	4	3	2
Belize	7	3				0				0	0	0	0
Bolivia*	10	4					2			1			
Brazil	5411	886	261	866	202	311	1176	5	85				
Canada*	1920	494		758		287	1100						
Chile*	897	129	1							2			
Colombia	968	223	104	87	110	15	71	0	1	2			
Costa Rica	135	28				21	61						
Cuba	270	58				4	44						
Dominican Republic*	175	11		9		12				2			
El Salvador	204	24		17	9	0	1	0	0	2			
Honduras	76	4				1	0						
Jamaica	100	8	0	16	12	8	36	1	1	1			
Mexico	1675	224	334	22						1			
Nicaragua*	119	22	23	22	8		55		3	3			
Panama	206	21	0	133	10	20	12	1	3				1
United States	11031	3429		8622	4266	1957	3343			25	45		103
Uruguay	152	13	20			2	106			1		1	
Venezuela	1035	312		457	242	40	302	3	20	2			1

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



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**C. Demographic details**

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	disordersB14. # other hereditary bleeding	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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**Eastern Mediterranean**

Algeria*	560	126	283										
Egypt*	3530	611		325	633								
Iran	2870	593		523	1006	82	3400			2	1		
Lebanon*	39	8		2		0	3						
Saudi Arabia	121	37		32		27	78						
Tunisia	235	37				10	45			13	23		

**Europe**

Albania	231	29				1	93			1			1
Armenia	157	5		2									
Austria	350	53				150	250	1		2	1	1	
Azerbaijan										4		1	
Belarus	473	72		800		0	600						
Belgium*	623	146		537	58								
Bosnia-Herzegovina	100	10		30									
Bulgaria	510	59	91	56	17	9	518	0	50		1		
Croatia	322	66		163	57	6	280	0	98			1	1
Cyprus	43	19		2									
Denmark	336	81	0	291	105	30	126	0	4	1	0	1	1
Estonia*	36	3		33	3	0	21	0	4				
Finland	219	61		1589	191								
Georgia	141	22	192	3	3	0	82	0	2	1			
Germany	4016	705		3036									
Greece	680	124		480	157	79	378	2	31	1	4	0	3
Hungary*	1004	223	0	1003	375	10	627	2	327				
Iceland	57	2	0	107	12	0	9	0	0				
Ireland	330	165		468	364	40	206	0	10		1		1
Israel						27	150			2	1		2
Italy*						820	2700						
Latvia	84	16		37		0	60	0	18	1			1



## C. Demographic details



Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	disorders 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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Lithuania	112	20	12	73	12	0	82						1
Macedonia*	169	67	12	23		0	47	0	0				
Malta*	12	3			4								
Moldova	180	14		15	5					1			
Netherlands	1400	100				158	1300						
Norway	271	91	0	710	44	9	0	0					
Poland	1918	309		670	138			6					
Portugal	520	94	6	43	10	63		2		1	1	1	5
Romania	1255	159	1	214	40	19	1088	0	30	3	2		1
Russia	7500	1500		3650									
Serbia & Montenegro	408	67		185	17	49	109	4	8		5		1
Slovak Republic	436	65	0	321	483	0	162	0	23				1
Slovenia	159	16	0	63	73	16	90	0	6	1			1
Spain	2005	376	3	1899	321	428	926	229	687	0	2	3	0
Sweden	663	167		1327		35		0		1	0	1	0
Switzerland	434	98	4	86	52						1		
Turkey	1035	229		92	40					6			
Ukraine*													
United Kingdom	5006	1103		5582	1632	405	2829	6	218	9	8	5	48
Uzbekistan	18	3	2	3	5		35		5	8		1	2

## South East Asia

Bangladesh	189	22			1					1			
China*													
India	2937	522	2049	25	68								
Indonesia	131	19	607	27	2	0	44						
Pakistan	393	45		49	17	0	200	0	7	5	0	2	2
Sri Lanka*													
Thailand	212	34		48	32	8	44						

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



WFH Global Survey 2003

**C. Demographic details**

Country	B10. # hemophilia A	B11. # hemophilia B	B12. # type unknown	B13. # vWD	disordersB14. # 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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**Western Pacific**

Australia													
Japan	3841	842	0	723	337	871	2436	7	118				
Korea*	1252	220	0	66	20	21	650	0	0	3			1
Malaysia	711	117	21	234	225	14	60	0	0	2			
Mongolia	29	4				0	3						
Nepal*	67	12	60		2		3						
New Zealand	350	90											
Philippines	538	93	53	11		1	19	0	0	3			
Singapore*	158	20	0	48	65	0	64						

<b>TOTALS:</b>	<b>79,344</b>	<b>16,191</b>								<b>126</b>	<b>103</b>	<b>21</b>	<b>181</b>
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## 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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### Africa

Kenya*	Sometimes	Sometimes	Never	Never	Always	Always	Never	Never
South Africa	Never	Always	Never	Sometimes	Always	Sometimes	Always	Sometimes
Zimbabwe*		Sometimes						

### Americas

Argentina	Sometimes	Always	Sometimes	Sometimes	Never	Rarely	Sometimes	Sometimes
Belize			Always	Sometimes				
Bolivia*	Sometimes		Rarely					
Brazil	Never	Always	Always	Always	Never	Never	Always	Always
Canada*		Rarely	Always				Always	Always
Chile*	Always	Sometimes	Rarely	Rarely	Always	Always	Rarely	Sometimes
Colombia	Rarely	Always	Sometimes	Sometimes		Rarely	Always	Sometimes
Costa Rica	Sometimes	Always	Never	Sometimes		Always	Sometimes	
Cuba	Always	Sometimes	Rarely	Never		Always		
Dominican Republic*	Rarely	Sometimes	Rarely	Rarely	Always	Rarely	Sometimes	Rarely
El Salvador	Sometimes	Sometimes	Never	Never	Always	Sometimes	Sometimes	Never
Honduras	Sometimes	Rarely	Rarely	Never				
Jamaica	Sometimes	Sometimes	Sometimes	Sometimes	Never	Always	Never	Never
Mexico	Always	Sometimes	Never	Sometimes	Always	Always	Sometimes	Sometimes
Nicaragua*	Sometimes	Sometimes	Never		Always	Sometimes	Rarely	Rarely
Panama	Rarely	Always	Never	Sometimes	Rarely	Always	Rarely	Sometimes
United States	Always	Always	Sometimes	Sometimes	Always	Always	Sometimes	Sometimes
Uruguay	Sometimes	Always	Rarely	Rarely				
Venezuela	Rarely	Always	Rarely	Always	Rarely	Rarely	Sometimes	Sometimes

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



**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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**Eastern Mediterranean**

Algeria*	Sometimes	Sometimes	Never	Never	Always	Sometimes	Sometimes	Never
Egypt*	Always	Always	Rarely	Always	Always	Always	Always	Always
Iran	Sometimes	Always	Rarely	Never		Sometimes	Always	Never
Lebanon*	Always	Sometimes	Never	Rarely				
Saudi Arabia	Never	Always	Never	Rarely	Never	Rarely	Sometimes	Sometimes
Tunisia	Always	Never	Never		Always		Never	

**Europe**

Albania	Sometimes	Sometimes	Rarely	Never				
Armenia	Sometimes	Rarely	Never	Never	Always	Sometimes	Never	Never
Austria	Never	Sometimes	Sometimes	Always	Never	Never	Sometimes	Sometimes
Azerbaijan	Rarely	Never	Rarely	Rarely	Always	Never	Never	Rarely
Belarus	Always	Rarely	Never	Never	Always	Sometimes	Never	Never
Belgium*	Never	Always	Always	Rarely	Never	Never	Always	Always
Bosnia-Herzegovina	Sometimes	Sometimes	Never	Never	Always	Sometimes	Never	Never
Bulgaria	Never	Always	Rarely	Sometimes	Rarely	Never	Always	Sometimes
Croatia	Never	Always	Always		Never	Never	Always	Sometimes
Cyprus	Never	Always	Rarely		Never	Never	Always	
Denmark	Never	Rarely	Always	Always	Never	Never	Always	Always
Estonia*	Never	Always	Never	Never	Never	Never	Always	Sometimes
Finland	Never	Always	Always	Sometimes	Never	Never	Always	Sometimes
Georgia	Always	Sometimes	Rarely	Never	Always	Always	Sometimes	Never
Germany	Never	Always	Always	Rarely	Never	Never	Always	Always
Greece	Never	Always	Always	Sometimes	Never	Never	Sometimes	Always
Hungary*	Never	Always	Always	Always				
Iceland	Never	Never	Always	Sometimes	Rarely	Never	Rarely	Sometimes
Ireland			Always				Always	Always
Israel	Rarely	Sometimes	Sometimes	Rarely	Rarely	Rarely	Sometimes	Sometimes
Italy*	Never	Always		Always	Never	Never	Always	Always
Latvia	Rarely	Always	Never	Always	Never	Never	Sometimes	Always
Lithuania		Always	Rarely	Sometimes	Sometimes		Sometimes	Always

## 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
Macedonia*	Always	Sometimes				Always		
Malta*		Always				Always		
Moldova	Always				Always	Always		
Netherlands	Never	Always	Never	Always	Always	Never	Always	Always
Norway	Never	Always	Always	Sometimes	Never	Rarely	Always	Always
Poland		Always		Rarely		Sometimes	Sometimes	Sometimes
Portugal	Rarely	Sometimes	Sometimes	Sometimes			Sometimes	Sometimes
Romania	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Sometimes	Rarely
Russia	Sometimes	Rarely	Never	Never	Always	Sometimes	Rarely	Rarely
Serbia & Montenegro	Sometimes	Always	Never	Sometimes	Never	Sometimes	Sometimes	Sometimes
Slovak Republic		Always	Rarely	Rarely			Always	Rarely
Slovenia		Always		Always			Always	Always
Spain	Never	Always	Always	Always	Rarely	Never	Always	Always
Sweden	Never	Rarely	Always	Rarely	Never	Never	Always	Rarely
Switzerland	Never	Sometimes	Sometimes	Sometimes	Never	Never	Sometimes	Sometimes
Turkey	Rarely	Always	Rarely	Always	Always	Rarely	Always	Always
Ukraine*	Always	Sometimes	Never	Rarely	Always	Always	Sometimes	Rarely
United Kingdom	Never	Sometimes	Sometimes	Sometimes	Never	Never		
Uzbekistan	Always	Never	Never	Never	Always	Always	Never	Never

### South East Asia

Bangladesh	Rarely	Sometimes	Sometimes	Never				
China*	Always	Sometimes	Rarely	Sometimes	Always	Always	Sometimes	Sometimes
India	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Sometimes	Sometimes
Indonesia	Always	Sometimes	Rarely	Never	Sometimes	Always	Sometimes	Never
Pakistan	Sometimes	Sometimes	Rarely	Rarely	Sometimes	Sometimes	Rarely	Rarely
Sri Lanka*	Always	Rarely	Never	Sometimes				
Thailand	Always	Always	Rarely	Sometimes	Rarely	Sometimes	Sometimes	Always

### Western Pacific

Australia		Always	Sometimes				Always	Always
Japan	Never	Always	Always	Rarely	Never	Never	Always	Never
Korea*	Never	Always	Rarely	Sometimes	Never	Always	Always	Sometimes

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



**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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Malaysia		Always					Sometimes	Always
Mongolia	Always	Rarely	Never	Never				
Nepal*	Sometimes	Rarely	Never	Rarely				
New Zealand		Sometimes	Sometimes	Sometimes			Sometimes	Sometimes
Philippines	Always	Always	Rarely	Never	Always	Always	Sometimes	Rarely
Singapore*	Always	Always	Never	Sometimes	Always	Always	Always	Sometimes

## E. Health care system



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Country	Population	Health care spending % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique
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### Africa

Kenya*	30,735,800	8.3	1	142	Factor assay
South Africa	43,240,000	8.8	10	1463	Factor assay
Zimbabwe*	12,820,650	7.3			Factor assay

### Americas

Argentina	37,488,000	8.6	11	1250	Factor assay
Belize	247,100	4.6	3	10	Factor assay
Bolivia*	8,515,200	6.7	1	14	Clotting screening test
Brazil	172,386,000	8.3	193	7626	Factor assay
Canada*	31,081,900	9.1			Factor assay
Chile*	15,402,000	7.2			Factor assay
Colombia	43,035,200	9.6	8	350	Factor assay
Costa Rica	3,873,000	6.4			Not known
Cuba	11,188,000	6.8	14	328	Factor assay
Dominican Republic*	8,505,200	6.3			Factor assay
El Salvador	6,400,000	8.8	3	171	Clinical symptoms
Honduras	6,584,700	6.8	1	60	Clotting screening test
Jamaica	2,590,000	5.5	3	108	Factor assay
Mexico	99,419,700	5.4	12	2000	Clotting screening test
Nicaragua*	5,205,000	4.4	1	196	Clotting screening test
Panama	2,897,000	7.6	2	41	Factor assay
United States	285,318,000	13	136	27348	Factor assay
Uruguay	3,361,000	10.9	5	149	Clinical symptoms
Venezuela	24,632,000	7.4	8	1200	Factor assay

### Eastern Mediterranean

Algeria*	30,835,000	3.6			Not known
Egypt*	65,176,900	3.8			Factor assay
Iran	64,528,200	5.5	10	3000	Factor assay
Lebanon*	4,384,700	12.4	4	39	Factor assay
Saudi Arabia	21,408,470	5.3			Factor assay
Tunisia	9,673,600	5.5	3		Factor assay

### Europe

Albania	3,164,400	3.4	1	100	Clotting screening test
Armenia	3,088,000	7.5	0		Clotting screening test

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



WFH Global Survey 2003

**E. Health care system**

Country	Population	Health care spending % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique
Austria	8,132,000	8	20	202	Factor assay
Azerbaijan	8,116,110	0.9	1	>60	Clinical symptoms
Belarus	9,970,260	5.7			Not known
Belgium*	10,286,000	8.7	10	1200	Factor assay
Bosnia-Herzegovina	4,060,000	4.5			Factor assay
Bulgaria	7,913,000	3.9	6	500	Clinical symptoms
Croatia	4,380,780	10	4	600	Factor assay
Cyprus	11,230,000	6.8	2	64	Not known
Denmark	5,359,000	8.3	2	813	Factor assay
Estonia*	1,364,000	6.1	3	39	Factor assay
Finland	5,188,000	6.6	1		Clotting screening test
Georgia	5,224,000	7.1	1	200	Clotting screening test
Germany	82,333,000	10.6			Factor assay
Greece	10,590,870	8.3	4	804	Factor assay
Hungary*	10,187,000	6.8	59	2605	Factor assay
Iceland	282,000	8.9	1	30	Factor assay
Ireland	3,839,000	6.7	5	1327	Factor assay
Israel	6,362,950	10.9	3	381	Factor assay
Italy*	5,7948,000	8.1	42	5000	Factor assay
Latvia	2,359,000	5.9	2	110	Factor assay
Lithuania	3,482,000	6	2	95	Factor assay
Macedonia*	2,035,000	6	1		Factor assay
Malta*	395,000	8.8			Not known
Moldova	4,270,000	3.5	2		Factor assay
Netherlands	16,039,000	8.1	16		Clotting screening test
Norway	4,513,000	7.8	1		Factor assay
Poland	38,641,000	6	32		Factor assay
Portugal	10,024,000	8.2	7		Factor assay
Romania	22,408,000	2.9	7		Clotting screening test
Russia	144,752,000	5.3	4		Factor assay
Serbia & Montenegro	10,651,000	5.6	8	300	Factor assay
Slovak Republic	5,404,000	5.9	44	380	Factor assay
Slovenia	19,920,000	8.6	1	311	Factor assay
Spain	41,117,000	7.7	34	3000	Factor assay
Sweden	8,894,000	10.7	3		Factor assay
Switzerland	7,231,000	10.7	19	674	Factor assay
Turkey	68,529,000	5	48	1396	Factor assay
Ukraine*	49,093,000	4.1			Clinical symptoms



## E. Health care system



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Country	Population	Health care spending % of GNP	C1. Number of HTC's	C2. Number of people cared for at HTC's	C3. Diagnostic technique
United Kingdom	58,800,000	7.3	23		Factor assay
Uzbekistan	2,506,800	5.3			Clinical symptoms

### South East Asia

Bangladesh	133,345,200	3.8	1	212	Factor assay
China*	1,271,850,000	5.3			Factor assay
India	1,032,355,000	4.9	55	9000	Factor assay
Indonesia	208,981,100	2.7	9	757	Clotting screening test
Pakistan	141,450,100	4.1	3		Clotting screening test
Sri Lanka*	18,732,000	3.6			Clinical symptoms
Thailand	61,183,900	3.7	26	1325	Factor assay

### Western Pacific

Australia	19,182,000	8.3	13		Factor assay
Japan	126,870,000	7.8	5	1000	Factor assay
Korea*	43,343,000	6	11	1400	Factor assay
Malaysia	23,802,400	2.5	36		Factor assay
Mongolia	2,421,400	6.6	3	33	Factor assay
Nepal*	23,584,700	4.2	1	139	Factor assay
New Zealand*	3,849,000	8	6		Factor assay
Philippines	78,317,000	3.4	1	60	Factor assay
Singapore*	4,131,000	3.5	3		Factor assay

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



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**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
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**Africa**

Kenya*						
South Africa	24,000,000	4,000,000				
Zimbabwe*	125,000	25,000				

**Americas**

Argentina	25,000,000	3,500,000				
Belize	110,000	60,000				
Bolivia*						
Brazil	160,000,000	21,000,000				450,000
Canada*						
Chile*	13,000,000	600,000				
Colombia	18,000,000	2,500,000	18,000,000	1,500,000		1,000,000
Costa Rica	5,050,000	2,292,000				
Cuba	248,920		248,920			
Dominican Republic*	250,000	30,000				
El Salvador	519,000		519,000			
Honduras	900,000					
Jamaica						
Mexico	32,600,000	3,100,000	32,600,000	3,100,000	0	0
Nicaragua*						
Panama	250,000	45,000			0	0
United States						
Uruguay	3,838,474	302,750				
Venezuela	25,022,670	5,826,000				30,000

## F. Use of factor concentrates



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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
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### Eastern Mediterranean

Algeria*	2,496,500	708,600				
Egypt*						
Iran	65,000,000	16,000,000				
Lebanon*	1,500,000	540,000				
Saudi Arabia						
Tunisia						

### Europe

Albania	800,000	20,000			20,000	
Armenia	11,875					
Austria						
Azerbaijan						
Belarus	15,000,000	300,000	15,000,000	30,000		
Belgium*						
Bosnia-Herzegovina						
Bulgaria	8,000,000	165,000	7,950,000	165,000	50,000	
Croatia	5,000,000	30,000				
Cyprus						
Denmark	21,300,000	4,800,000	2,000,000	0	19,300,000	4,800,000
Estonia*	1,610,000	108,000				
Finland						
Georgia	1,150,800	331,000	1,150,800	331,000		
Germany	450,000,000	50,000,000	240,000,000		210,000,000	
Greece	16,642,678	3,355,504	4622474	404,822	12,020,204	2,950,682
Hungary*	31,000,000	2,000,000				
Iceland	3,200,000	10,000			3,200,000	10,000
Ireland	19,301,746	11,180,310	2,082,500	0	17,219,246	11,180,310
Israel						
Italy*						
Latvia	1,450,000	194,000	1,450,000	194,000		
Lithuania						
Macedonia*	250,000	250,000				
Malta*						
Moldova						

(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



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**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
Netherlands						
Norway						
Poland	53,246,177	7,000,000	53,246,177	7,000,000		
Portugal	30,088,750	4,991,500	16,252,500	4,491,500	13,836,250	500,000
Romania	2,000,000	814,000	2,000,000	814,000		
Russia	21,500,000	7,000,000	21,500,000	7,000,000		
Serbia & Montenegro	3,468,000	302,000	3,468,000	302,000		
Slovak Republic	14,800,000	1,200,000	14,800,000	1,200,000	0	0
Slovenia	7,077,721	545,500	7,177,721	545,500	0	0
Spain	103,000,000	17,000,000	41,000,000	11,000,000	62,000,000	6,000,000
Sweden	62,605,000	10,648,000				
Switzerland	22,290,750	4,062,200	9,036,250	3,755,200	13,254,500	307,000
Turkey	21,795,000	3,416,000	21,795,000	3,416,000	0	0
Ukraine*	800,000	100,000				
United Kingdom	195,000,000	32,000,000				
Uzbekistan						

**South East Asia**

Bangladesh	467,990	52,000	456,220	42,000	11,770	10,000
China*						
India	7,000,000	1,000,000				
Indonesia	1,711,700	196,000	1,254,500	160,000	457,200	36,000
Pakistan	447,808	97,360				
Sri Lanka*						
Thailand						

## F. Use of factor concentrates



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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
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### Western Pacific

Australia						
Japan	233,440,000		121,430,000		112,010,000	
Korea*	51,016,250	8,522,250				
Malaysia					0	0
Mongolia	63,080	15,000	1500		0	0
Nepal*	161,617	85,870				
New Zealand*						
Philippines	966,525	345,000	959,544	345,000	6981	0
Singapore*	2,000,000	300,000				

<b>TOTALS:</b>	<b>1,787,574,031</b>	<b>232,965,844</b>	<b>640,001,106</b>	<b>45,796,022</b>	<b>463,386,151</b>	<b>27,273,992</b>
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(Data collected in 2003, except \* collected in 2002)

(GNP, population, life expectancy and health care spending data World Bank 2001)



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**G. Products used****D4. Factor VIII Concentrates**

Brand Name	Manufacturer	Countries reporting use	Price range per IU
Aafact	Sanquin, CLB	Germany; Netherlands	
AHF (High Purity)	CSL Ltd.	Australia; Malaysia; New Zealand	
Alphanate	Alpha	Brazil; India; Malaysia; Pakistan; Philippines; Saudi Arabia; Thailand; United Kingdom; United States	US\$0.28 - 1.00
Amofil	Finnish Red Cross BTS	Finland	
Beriate P = Beriate HS	Aventis Behring	Austria; Brazil; Mexico; Portugal; Romania; Serbia; Slovak Republic; Spain; Switzerland; Turkey; United Kingdom	US\$0.30 - 0.69
Biostate (Factor VIII)	CSL Ltd.	Australia	
Conco-eight-HT	Benesis	Japan	
Confact F	Kaketsuken	Japan	
Cross Eight M	Japanese Red Cross	Japan	
Emoclot D.I.	Kedrion	Cuba; Georgia; India; Portugal; Russia; Turkey	US\$0.10 - 0.41
FACTANE	LFB	India	
Factor 8 Y	Bio Products Laboratory	Brazil; Colombia; Cuba; India; Israel; Latvia; Turkey; United Kingdom	US\$0.08 - 0.38
Fanhdi	Grifols	Argentina; Brazil; Bulgaria; Germany; Ireland; Mexico; Slovak Republic; Spain; Turkey; United Kingdom; Venezuela	US\$0.30 - 1.12
GreenEight	Greencross PD	Honduras	
Haemate P = Haemate HS	Aventis Behring	Austria; Denmark; Finland; Germany; Greece; India; Indonesia; Israel; Netherlands; Norway; Pakistan; Portugal; Romania; Serbia; Slovak Republic; Slovenia; Spain; Switzerland; Turkey; United Kingdom	US\$0.62 - 0.89
Haemoctin SDH (=Faktor VIII Intersero)	Intersero	Austria; Bangladesh; Bosnia-Herzegovina; Colombia; Germany; India; Iran; Latvia; Lithuania; Mongolia; Pakistan	US\$0.22 - 0.76
Helixate FS = Helixate NexGen	Aventis Behring	Austria; Denmark; India; Israel; Spain; United Kingdom; United States	US\$0.89 - 1.38
Hemofil M AHF	Baxter	Argentina; Brazil; Bulgaria; Colombia; Finland; Georgia; Greece; India; Israel; Latvia; Lithuania; Malaysia; Mexico; Netherlands; Pakistan; Panama; Philippines; Poland; Portugal; Russia; Slovak Republic; Slovenia; Spain; Thailand; Turkey; United Kingdom; United States; Venezuela	US\$0.21 - 1.06
HEMORAAS-HP, SD plus H	Shanghai RAAS	Georgia	
Humate P	Aventis Behring	India; Israel; Netherlands; Saudi Arabia; United States	
HYATE:C	IPSEN, Inc.	United States	

## G. Products used



Brand Name	Manufacturer	Countries reporting use	Price range per IU
Immunate	Baxter Bioscience	Argentina; Austria; Colombia; Germany; Greece; India; Israel; Lithuania; Netherlands; Norway; Poland; Romania; Russia; Serbia; Slovak Republic; Switzerland; Turkey; Venezuela	US\$0.10 - 0.82
Koate DVI	Bayer	Belarus; Bosnia-Herzegovina; Bulgaria; Colombia; Costa Rica; El Salvador; Georgia; India; Indonesia; Iran; Israel; Lithuania; Mongolia; Pakistan; Panama; Philippines; Russia; Saudi Arabia; Turkey; United States; Uruguay	US\$0.17 - 0.92
Kogenate FS = Kogenate Bayer (in EU)	Bayer	Australia; Austria; Bosnia-Herzegovina; Denmark; Germany; Greece; Honduras; Ireland; Israel; Japan; Netherlands; New Zealand; Norway; Pakistan; Portugal; Spain; Switzerland;	US\$0.68 - 2.03
Monarc-M	American Red Cross	Argentina; Belize; Brazil; Germany; India; Israel; Pakistan; United States; Uruguay; Venezuela	US\$0.35 - 1.13
Monoclate P	Aventis Behring	Germany; India; Israel; Jamaica; Mongolia; United Kingdom; United States	US\$0.56 - 0.95
Octanate	Octapharma	Austria; El Salvador; Finland; Germany; Mexico; Norway; Poland; Russia; Serbia; Slovenia; Turkey; Venezuela	US\$0.30 - 0.75
Octonativ-M	Octapharma	Finland; Germany; Iran; Pakistan	
Profilate	Grifols	Germany	
Recombinate	Baxter Bioscience	Australia; Austria; Cuba; Denmark; Finland; Germany; Greece; Iceland; India; Ireland; Israel; Japan; Netherlands; New Zealand; Norway; Portugal; Spain; Switzerland; United Kingdom; United States	US\$0.57 - 1.33
ReFacto	Wyeth	Australia; Austria; Bulgaria; Denmark; Germany; Greece; Ireland; Israel; Netherlands; New Zealand; Norway; Portugal; Spain; United Kingdom; United States	US\$0.57 - 1.36
Replenate	Bio Products Laboratory	India; Israel; United Kingdom	

### D5. Factor IX Concentrates

Brand Name	Manufacturer	Countries reporting use	Price range per IU
Aimafix D.I.	Kedrion	Belarus; Georgia; India; Iran; Russia; Turkey; Venezuela	US\$0.10 - 0.38
Alphanine SD	Alpha	Bosnia-Herzegovina; Israel; Malaysia; Pakistan; United Kingdom; United States	US\$0.44 - 1.10
Bemofil	Finnish Red Cross BTS	Finland	
BeneFIX	Wyeth	Argentina; Australia; Brazil; Colombia; Denmark; Israel; Netherlands; New Zealand; Pakistan; Spain; Switzerland; United States; Venezuela	US\$0.59 - 1.18



**G. Products used**

Brand Name	Manufacturer	Countries reporting use	Price range per IU
BeneFIX	Baxter SA	Austria; Finland; Germany; Greece; Iceland; India; Ireland; Netherlands; Pakistan; Portugal; United Kingdom	US\$0.70 - 1.50
Berinin-P = Berinin HS	Aventis Behring	Germany; Indonesia; Mexico; Serbia; Switzerland; Turkey	US\$0.35 - 0.75
BETAFACT	LFB	Greece; Turkey	
Christmassin-M	Benesis	Japan	
Faktor IX SDN	Biotest	Austria	
Immunine	Baxter	Argentina; Austria; Belize; Bosnia-Herzegovina; Bulgaria; Colombia; Germany; Greece; India; Lithuania; Netherlands; Poland; Romania; Russia; Slovak Republic; Spain; Switzerland; Turkey; Venezuela	US\$0.40 - 0.77
Mono FIX-VF	CSL	Australia; New Zealand	
Mononine	Aventis Behring	Austria; Germany; Greece; India; Israel; Jamaica; Netherlands; Pakistan; United Kingdom; United States	US\$0.48 - 1.18
Nanotiv	Octapharma	Finland; Iran	
Nonafact	Sanquin	Netherlands; Saudi Arabia	
Novact M	Kaketsuken	Japan	
Octanine F	Octapharma	Finland; Georgia; Norway; Poland; Portugal; Slovenia; Uruguay; Venezuela	US\$0.24 - 0.70
Octanyne	Octapharma	Brazil; El Salvador; Finland; Israel; Mexico; Russia; Turkey	US\$0.35 - 0.87
Replenine – VF	Bio Products Laboratory	Latvia; Turkey; United Kingdom	US\$0.33 - 0.43

**D6. Prothrombin Complex Concentrates**

Brand Name	Manufacturer	Countries reporting use	Price range per IU
Autoplex-T	NABI, Boca Raton, Florida, USA	India; Israel; Jamaica; Netherlands; United States; Venezuela	US\$1.12 - 1.50
Bebulin VH	Baxter	Austria; India	
Beriplex P/N	Aventis Behring	Austria; Germany; United Kingdom	US\$0.55 - 0.58
Cofact (= PPSB in Belgium)	Sanquin	Netherlands	
Faktor IX HS	Aventis Behring	Spain	
FEIBA VH	Baxter	Argentina; Australia; Austria; Brazil; Colombia; Finland; Germany; Greece; India; Iran; Ireland; Israel; Jamaica; Japan; Latvia; Lithuania; Netherlands; New Zealand; Norway; Poland; Portugal; Russia; Saudi Arabia; Slovak Republic; Slovenia; Spain; Switzerland; United Kingdom; United States; Venezuela	US\$0.62 - 1.55
KASKADIL	LFB	Turkey	
Profilnine SD	Alpha	Brazil; Costa Rica; India; Malaysia; Pakistan; Philippines; Thailand; United States	US\$0.26 - 0.75



## G. Products used



Brand Name	Manufacturer	Countries reporting use	Price range per IU
Proplex-T	Baxter	Bulgaria; Costa Rica; India; Japan; Panama; Slovenia; Venezuela	US\$0.28 - 0.70
Prothoraa SD plus Nanofil	Shanghai RAAS	Georgia; Pakistan	
Prothrombinex- HT	CSL	Australia; Malaysia; New Zealand	
Prothrombinkomplex NDS	German Red Cross BSD NSTOB	Germany	
Prothromplex-T	Baxter	Brazil; Colombia; India; Ireland; Poland; Slovak Republic; Switzerland	US\$0.29 - 1.08
UMAN Complex D.I.	Kedrion	India; Venezuela	

### D7. Other Products

Brand Name	Manufacturer	Countries reporting use	Price range per IU
FACTEUR VII	LFB	Israel	
Facteur von Willebrand	LFB	Greece	
Factor VII	Bio Products Laboratory	Australia; Saudi Arabia	
Factor VII	Baxter	Australia; Colombia; Greece; Lithuania; Poland; Slovak Republic; Switzerland	US\$0.50 - 1.26
Factor XI	Bio Products Laboratory	United Kingdom	
Fibrinogen	SNBTS	Bulgaria	
Fibrinogen HT	Benesis	Israel	
Fibrogammin HS = Fibrogammin P (Factor XIII)	Aventis Behring	Denmark; Germany; Greece; Lithuania; Netherlands; Poland; Slovak Republic; United Kingdom	US\$0.29 - 0.60
Haemocomplettan HS = Haemocomplettan P (fibrinogen)	Aventis Behring	Denmark; Germany; Greece; Turkey; United Kingdom	
HEMOLEVEN (Factor XI)	LFB	Israel	
NovoSeven (Factor VIIa) = Niasase (Canada)	NovoNordisk	Australia; Brazil; Bulgaria; Denmark; Finland; Greece; Iceland; India; Iran; Ireland; Israel; Japan; Latvia; Malaysia; Netherlands; Norway; Philippines; Poland; Portugal; Romania; Russia; Saudi Arabia; Serbia; Slovak Republic; Slovenia; Spain; Switzerland; Thailand; Turkey	
Thrombin	SNBTS	Saudi Arabia	



**Sample survey****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 <b>hemophilia A and B</b> (PWH)		<input type="checkbox"/>
B2. Number of identified people with <b>von Willebrand disease</b> (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 <b>registry</b> 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"/>

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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## Sample survey

### 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		



**Sample survey****Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2002)**

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 <b>Hemophilia treatment centres</b> 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**

<b><u>HIV</u></b>	<b>Yes</b>	<b>No</b>
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"/>
<b><u>Hepatitis A</u></b>		
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"/>
<b><u>Hepatitis B</u></b>		
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**

<b>Hepatitis C</b>		
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"/>



**Sample survey****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 <b>plasma-derived</b> concentrates were used in your country last year?			<input type="checkbox"/>
D3. How many international units of <b>recombinant</b> concentrates were used in your country last year?			<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.	
<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"/>	Fanhdi	Grifols	
<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	

**Sample survey**

<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"/>	Monoclade 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.)



**Sample survey**

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"/>	Prothoraa 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	
<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) = Niasase (Canada)	NovoNordisk	
<input type="checkbox"/>	Thrombin	SNBTS	
<input type="checkbox"/>	WILFACTIN	LFB	





## Sample survey

### 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

**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.

