

# World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2005

*Report on the Annual Global Survey 2005* is published by the World Federation of Hemophilia.

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## Table of Contents

Introduction.....	1
Summary of survey data.....	3
Countries included in the survey.....	4
Population statistics .....	5
Demographic details .....	8
Reported Use of treatment products .....	11
Healthcare system.....	14
Use of factor concentrates.....	17
Factor use per capita.....	20
Products used.....	21
Annual Global Survey 2005 sample questionnaire.....	26
Glossary.....	34





## **Introduction to the Report on the WFH Global Survey 2005**

*Report on the Annual Global Survey 2005* includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (vWD), other rare bleeding disorders, and platelet disorders throughout the world. The purpose of this report is to provide useful information to hemophilia organizations, hemophilia treatment centres (HTCs), and health officials involved in efforts to reduce or prevent complications of bleeding disorders in order to assist with program planning.

### **Methodology**

In 1998, the World Federation of Hemophilia (WFH) began collecting information on hemophilia care throughout the world. This survey, called the WFH Global Survey, collects basic demographic information, data on resources of care and treatment products, and information on the prevalence (the percentage of the population affected) of infectious complications such as HIV and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization.

The 2005 survey is the seventh WFH survey. It gathers data for the years 2004 and 2005. The survey includes data on more than 190,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 98 countries.

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

### **Comments on data collection**

Participation in the survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. This year national hemophilia organizations have supplied more complete data than last year.

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.





## **2005 WFH Global Survey Summary**

### **Demographics**

Number of countries in this survey: **98**

Percentage of world population covered by 2005 survey: **88%**

Number of people identified with hemophilia A and B (question B1) : **131,264**

Number of people identified with vWD (question B2): **45,001**

Number of people identified with other bleeding disorders (question B3): **16,735**

Total number of people with bleeding disorders identified: **193,000**

Number of people with hemophilia A (question B10): **103,086**

Number of people with hemophilia B (question B11): **20,632**

Number of countries using national registries to report these numbers: **49**

Reported number of PWH infected with HIV: **6,762**

Reported number of PWH infected with HCV: **20,113**

### **Factor usage**

*(56 countries reporting)*

Per capita factor VIII usage (GNP above US\$10,000): **3.54 IU**

Per capita factor IX usage (GNP above US\$10,000): **0.60 IU**

Per capita factor VIII usage (GNP between US\$2000-US\$10,000): **0.82 IU**

Per capita factor IX usage (GNP between US\$2000-US\$10,000): **0.17 IU**

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

Per capita factor IX usage (GNP below US\$2,000): **0.002 IU**

Total reported consumption of factor VIII concentrates: **2,356,498,054 IU**

Total reported consumption of factor IX concentrates: **428,439,368 IU**



### Countries included in the 2005 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. 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. Kuwait
52. Latvia
53. Lebanon†
54. Lithuania
55. Macedonia†
56. Malaysia
57. Malta\*
58. Mexico
59. Moldova
60. Mongolia†
61. Nepal
62. Netherlands
63. New Zealand
64. Nicaragua\*
65. Nigeria
66. Norway
67. Pakistan
68. Palestine†
69. Panama
70. Peru
71. Philippines†
72. Poland
73. Portugal
74. Romania
75. Russia
76. Saudi Arabia†
77. Senegal†
78. Serbia and Montenegro
79. Singapore
80. Slovak Republic†
81. Slovenia†
82. South Africa
83. Spain
84. Sri Lanka†
85. Sudan
86. Sweden
87. Switzerland
88. Thailand
89. Tunisia\*
90. Turkey
91. Ukraine
92. United Kingdom
93. United States
94. Uruguay†
95. Uzbekistan
96. Venezuela
97. Viet Nam
98. Zimbabwe†

All data collected in 2005 except:

\* collected in 2003

† collected in 2004





**Population Statistics**

Country	Data Year	Population	B1. No. of people with hemophilia	B2. No. of people with vWD	B3. No. of people with other bleeding disorders	B4. Source of data
Albania	2005	3,130,000	267		2	Registry
Algeria	2004	32,854,000	977			Survey
Argentina	2005	38,747,000	1,982			Registry
Armenia	2004	3,016,000	162	2		Survey
Australia	2005	20,155,000	1,605	1,125	292	Registry
Austria	2004	8,189,000	456	30		Survey
Azerbaijan	2005	8,411,000	800	200	4	Registry
Bangladesh	2005	141,822,000	298	0	6	Registry
Belarus	2004	9,755,000	560	800		
Belgium	2003	10,419,000	762	553	49	Survey
Belize	2004	270,000	14	3	1	Registry
Bolivia	2003	9,182,000	14			
Bosnia-Herzegovina	2004	3,907,000	140	30		
Brazil	2005	186,405,000	6,297	886	202	Other
Bulgaria	2005	7,726,000	600	56	20	Registry
Canada	2005	32,268,000	2,856	2,366	725	Registry
Chile	2003	16,295,000	1,027			Registry
China	2004	1,315,844,000	4,131	227		Survey
Colombia	2005	45,600,000	1,461	112	87	Survey
Costa Rica	2005	4,327,000	167			Registry
Croatia	2005	4,551,000	518	192	60	Registry
Cuba	2005	11,269,000	359			Registry
Cyprus	2004	835,000	103	12	5	Other
Denmark	2005	5,431,000	445	334	109	Survey
Dominican Republic	2003	8,895,000	186	9		Survey
Ecuador	2005	13,228,000	337	32	43	Registry
Egypt	2005	74,033,000	3,959	375	753	Registry
El Salvador	2004	6,881,000	254	15	7	Other
Eritrea	2004	4,401,000	23			Other
Estonia	2003	1,330,000	39	33	3	
Finland	2005	5,249,000	297	1,700	243	Registry
France	2005	60,496,000	3,506	375	137	Survey
Georgia	2005	4,474,000	218	12	12	Registry
Germany	2005	82,689,000	4,800	3,100		Registry
Greece	2005	11,120,000	841	712	142	Survey
Guatemala	2005	12,599,000	123	14	72	Survey
Honduras	2005	7,205,000	171			Survey
Hungary	2005	10,098,000	1,094	1,416	551	Registry
Iceland	2005	295,000	59	53	12	Registry
India	2005	1,103,371,000	12,094			Survey
Indonesia	2005	222,781,000	1,103	27	2	Survey
Iran	2005	69,515,000	4,715	638	1,153	Registry





Country	Data Year	Population	B1. No. of people with hemophilia	B2. No. of people with vWD	B3. No. of people with other bleeding disorders	B4. Source of data
Iraq	2005	28,807,000	677	102	111	Survey
Ireland	2005	4,148,000	600	569	462	Registry
Israel	2005	6,725,000	473			Survey
Italy	2005	58,093,000	5,319	2,275	1,488	Registry
Jamaica	2004	2,651,000	108	16	13	Registry
Japan	2005	128,085,000	4,810	764	355	Survey
Kenya	2004	34,256,000	425	13	2	Registry
Korea	2005	47,817,000	1,668	94	53	Registry
Kuwait	2005	2,687,000				
Latvia	2005	2,307,000	110	39		Survey
Lebanon	2004	3,577,000	110	38	16	Other
Lithuania	2005	3,431,000	148	110	30	Survey
Macedonia	2004	2,034,000	208	18		Survey
Malaysia	2005	25,347,000	1,000	341	313	Registry
Malta	2003	402,000	15		4	
Mexico	2005	107,029,000	3,052	60		Other
Moldova	2005	4,206,000	194			Survey
Mongolia	2004	2,646,000	40	1		Registry
Nepal	2005	27,133,000	165	216	4	Survey
Netherlands	2005	16,299,000	1,600		50	
New Zealand	2005	4,028,000	300	119	1	Registry
Nicaragua	2003	5,487,000	164	22	8	Survey
Nigeria	2005	131,530,000	42	3	4	Other
Norway	2005	4,620,000	379	823	41	Registry
Pakistan	2005	157,935,000	743	103	50	Registry
Palestine	2004	3,702,000	125	5	48	Registry
Panama	2005	3,232,000	227	274	14	Other
Peru	2005	27,968,000	498	80	14	Registry
Philippines	2004	83,054,000	787	11	44	Registry
Poland	2005	38,530,000	2,487	733	256	Registry
Portugal	2005	10,495,000	591	47	10	Other
Romania	2005	21,711,000	1,432	231	45	Registry
Russia	2005	143,202,000	4,560	1,175	720	Registry
Saudi Arabia	2004	24,573,000	170	42		Other
Senegal	2004	11,658,000	137		2	Survey
Serbia & Montenegro	2005	10,503,000	495	203	14	Registry
Singapore	2005	4,326,000	198	58	84	Registry
Slovak Republic	2004	5,401,000	502	332	524	Registry
Slovenia	2004	19,920,000	175	63	73	Registry
South Africa	2005	47,432,000	1,617	474	205	Registry
Spain	2005	43,064,000	1,893	674	324	Survey
Sri Lanka	2004	20,743,000	148			Other
Sudan	2005	36,233,000	300	30	9	Registry
Sweden	2005	9,041,000	731			





<b>Country</b>	<b>Data Year</b>	<b>Population</b>	<b>B1. No. of people with hemophilia</b>	<b>B2. No. of people with vWD</b>	<b>B3. No. of people with other bleeding disorders</b>	<b>B4. Source of data</b>
Switzerland	2005	7,252,000	559	89	44	Registry
Thailand	2005	64,233,000	1,325	69	56	Registry
Tunisia	2003	9,673,600	272			Survey
Turkey	2005	73,193,000	2,455	137	143	Registry
Ukraine	2005	46,481,000				
United Kingdom	2005	59,668,000	8,167	7,709	4,364	Registry
United States	2005	298,213,000	15,224	10,742	1,553	Survey
Uruguay	2004	3,463,000	199			Registry
Uzbekistan	2005	26,593,000	908	77	12	Survey
Venezuela	2005	26,749,000	1,626	548	363	Registry
Viet Nam	2005	84,238,000	936	18	117	Registry
Zimbabwe	2004	13,010,000	350	15		Survey
<b>TOTALS:</b>		<b>5,707,902,600</b>	<b>131,264</b>	<b>45,001</b>	<b>16,735</b>	



## Demographic Details

- B10.** Hemophilia A
- B11.** Hemophilia B
- B12.** Hemophilia, type unknown
- B13.** von Willebrand disease
- B14a.** Other hereditary bleeding disorders: Factor I deficiency
- B14b.** Other hereditary bleeding disorders: Factor II deficiency
- B14c.** Other hereditary bleeding disorders: Factor V deficiency
- B14d.** Other hereditary bleeding disorders: Factor V+VIII deficiency
- B14e.** Other hereditary bleeding disorders: Factor VII deficiency
- B14f.** Other hereditary bleeding disorders: Factor X deficiency
- B14g.** Other hereditary bleeding disorders: Factor XI deficiency
- B14h.** Other hereditary bleeding disorders: Factor XIII deficiency
- B14i.** Other hereditary bleeding disorders: platelet disorders
- B14j.** Other hereditary bleeding disorders: type unknown

Country	B10. No. of hemophilia A	B11. No. of hemophilia B	B12. No. of type unknown	B13. No. of vWD	B14A. No. of FID	B14B. No. of FIID	B14C. No. of FVD	B14D. No. of FV+VIII	B14E. No. of FVIIID	B14F. No. of FXD	B14G. No. of FXID	B14H. No. of FXIID	B14I. No. of platelet disorder	B14J. No. of OBD-unknown
Albania	247	20												2
Algeria	809	163	5											
Argentina	1,727	255												
Armenia	157	5		2										
Australia	1,296	309	0	1,124									76	193
Austria	350	53	53	30										
Azerbaijan														
Bangladesh	260	38			2								1	5
Belarus	480	70		800										
Belgium	623	146		537										58
Belize	11	3		3										1
Bolivia	10	4												
Bosnia-Herzegovina	100	10		30										
Brazil	5,411	886	261	866										202
Bulgaria	507	60	29	56	5				9	3	3			
Canada	2,291	565	0	2,366										725
Chile	897	129	1											
China	2,432	278		227										
Colombia	1,016	234	111	112	17	9	0	0	8	0	7	4	24	15
Costa Rica	139	28							2	1	2	3		
Croatia	442	76	0	192	2	0	3	3	22	2	8	10	3	7
Cuba	296	63												
Cyprus	52	61		12										5
Denmark	352	93	0	334	0	1	2	0	35	7	6	9	22	
Dominican Republic	175	11		9										
Ecuador	305	32	33	32	1				1	1	5	1	1	



Country	B10. No. of hemophilia A	B11. No. of hemophilia B	B12. No. of type unknown	B13. No. of vWD	B14A. No. of FID	B14B. No. of FIID	B14C. No. of FVD	B14D. No. of FV+VIIIID	B14E. No. of FVIID	B14F. No. of FXD	B14G. No. of FXID	B14H. No. of FXIIID	B14I. No. of platelet disorder	B14J. No. of OBD-unknown
Egypt	3,203	756		375	97		130	3	57	64	78	4	298	24
El Salvador	229	25		15										5
Eritrea	22	1												
Estonia	36	3		33										3
Finland	232	65	0	1,700	14	1	5	0	4	4	2	13	200	
France	2,901	605	0	375										137
Georgia	186	35	0	12								1		12
Germany	4,055	745		3,100										
Greece	714	127		712	5		2	2	31	7	25	12	58	
Guatemala	114	9		14										72
Honduras	132	15	24											
Hungary	875	219	0	1,416										551
Iceland	57	2	0	53									12	
India	9,526	1,697	871											
Indonesia	192	27	884	27										
Iran	3,890	815		638	51	9	52	112	116	76	30	108	522	31
Iraq	510	167		102	18		1		30	4	1	11	45	1
Ireland	391	209		569			180		37	46	37	3	86	30
Israel	372	71	30											
Italy	3,921	649	162	2,248										1467
Jamaica	101	8	0	16										12
Japan	3,938	872	0	764	49	5	19	7	40	15	19	44		
Kenya	377	46	16	7	45									
Korea	1,381	287	2	94	3		2		15		10	2		19
Kuwait														
Latvia	91	17		39										
Lebanon	88	22		38										16
Lithuania	128	20		110			2		18	1	3	3		
Macedonia	149	59		18										
Malaysia	847	153		341	4	2	12		49	11	25	11	105	94
Malta	12	3												4
Mexico	2,659	393	275	60										
Moldova														
Mongolia	35	5	0	1										
Nepal	133	27	51						1	3				1
Netherlands	1,450	50			4		1		25			10		
New Zealand	248	52	0	119										1
Nicaragua	119	22	23	22										8
Nigeria	32	5	5	3										
Norway	283	96		823	2		2		25					
Pakistan	625	118	8	103	2	2	16		6	6			7	3
Palestine	100	25		5										48
Panama	202	25	0	274					3	9			2	





Country	B10. No. of hemophilia A	B11. No. of hemophilia B	B12. No. of type unknown	B13. No. of vWD	B14A. No. of FID	B14B. No. of FIID	B14C. No. of FVD	B14D. No. of FV+VIIID	B14E. No. of FVID	B14F. No. of FXD	B14G. No. of FXID	B14H. No. of FXIID	B14I. No. of platelet disorder	B14J. No. of OBD-unknown
Peru	348	52	98	80	0	1	2	0	4	1	4	1	2	0
Philippines	682	105	44	11										
Poland	2,150	337		733										
Portugal	491	100	38	47	2	0	3	0	0	1	4	0	0	0
Romania	1,271	161		231										45
Russia	3,942	618		1,175										
Saudi Arabia	129	38	3	42										
Senegal	137	0												2
Serbia & Montenegro	426	69		203	1			2	2		4	2		3
Singapore	173	25	0	58	0	0	15	0	9	0	45	3		
Slovak Republic	437	64	0	332										524
Slovenia	159	16	0	63										73
South Africa	1,359	258	0	474	9	0	41	4	17	10	29	4	82	1
Spain	1,626	267		674										324
Sri Lanka	111	12	15											
Sudan														
Sweden														
Switzerland	458	101	0	89	9	0	0	2	18	2	0	13		
Thailand	393	67		69				1	10				27	
Tunisia	235	37												
Turkey	2,040	415	0	137	0	1	5	13	58	29	3	2	4	28
Ukraine														
United Kingdom	6,674	1,479	0	7,709	177	13	106	23	449	162	1407	46	981	253
United States	11,661	3,563	0	10,742	82	64	149	0	527	86	539	106		
Uruguay	152	9												
Uzbekistan	798	110		77	0	1	0	0	6	0	23	0	0	0
Venezuela	1,268	358	0	548	42	58	19	0	54	41	127	7	0	15
Viet Nam	725	182	28	18	1	0	0	16	1	5	0	1	91	4
Zimbabwe	300	50		1										
<b>TOTALS:</b>	<b>103,086</b>	<b>20,632</b>												

**Reported Use of Treatment Products**

<b>Country</b>	<b>B17. Reported use: plasma</b>	<b>B18. Reported use: cryo</b>	<b>B19. Reported use: plasma-derived conc.</b>	<b>B20. Reported use: recombinant</b>	<b>B21. Reported use: DDAVP</b>
Albania	Sometimes	Sometimes	Rarely	Rarely	Rarely
Algeria	Always	Sometimes	Sometimes	Never	Rarely
Argentina	Never	Rarely	Always	Sometimes	Sometimes
Armenia	Always	Sometimes	Rarely	Never	Never
Australia	Rarely	Rarely	Sometimes	Always	Always
Austria	Never	Never	Sometimes	Sometimes	Rarely
Azerbaijan	Always	Rarely	Rarely	Rarely	Never
Bangladesh	Sometimes	Rarely	Sometimes	Sometimes	Never
Belarus	Rarely	Sometimes	Sometimes	Never	Never
Belgium	Never	Never	Always	Always	Rarely
Belize			Always		Sometimes
Bolivia		Sometimes		Rarely	
Bosnia-Herzegovina	Always	Sometimes	Sometimes	Never	Never
Brazil	Never	Rarely	Always	Rarely	Sometimes
Bulgaria	Never	Never	Always	Rarely	Rarely
Canada	Never	Never	Sometimes	Always	Sometimes
Chile	Always	Always	Sometimes	Rarely	Rarely
China	Always	Sometimes	Sometimes	Rarely	Rarely
Colombia			Always	Sometimes	Sometimes
Costa Rica		Sometimes	Always	Sometimes	Always
Croatia	Never	Rarely	Sometimes	Sometimes	Sometimes
Cuba	Sometimes	Always	Sometimes	Sometimes	Rarely
Cyprus			Always	Rarely	
Denmark	Never	Never	Never	Always	Always
Dominican Republic	Always	Rarely	Sometimes	Rarely	Rarely
Ecuador	Always	Always	Rarely	Rarely	Rarely
Egypt	Always	Always	Rarely	Rarely	Sometimes
El Salvador	Sometimes	Sometimes	Rarely	Rarely	Never
Eritrea	Sometimes			Always	
Estonia	Never	Never	Always	Never	Never
Finland	Never	Never	Always	Always	Rarely
France	Never	Rarely	Sometimes	Sometimes	Sometimes
Georgia	Rarely	Rarely	Always	Rarely	Rarely
Germany	Never	Never	Always	Always	Rarely
Greece	Never	Never	Sometimes	Always	Sometimes
Guatemala		Always	Sometimes	Rarely	
Honduras	Sometimes	Rarely	Always	Never	
Hungary	Never	Never	Sometimes	Sometimes	Sometimes
Iceland	Never	Never	Never	Always	Sometimes
India	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Indonesia	Always	Always	Sometimes	Rarely	Never
Iran	Always	Always	Always	Never	Rarely
Iraq	Sometimes	Sometimes	Sometimes	Sometimes	Rarely





Country	B17. Reported use: plasma	B18. Reported use: cryo	B19. Reported use: plasma-derived conc.	B20. Reported use: recombinant	B21. Reported use: DDAVP
Israel	Rarely	Rarely	Sometimes	Sometimes	Rarely
Italy	Never	Never	Always	Always	
Jamaica	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Japan	Never	Never	Always	Always	Rarely
Kenya	Always	Sometimes	Sometimes	Sometimes	Never
Korea	Never	Never	Always	Always	Always
Kuwait	Never	Never	Always	Never	Never
Latvia	Rarely	Rarely	Always	Never	Always
Lebanon	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Lithuania	Never	Never	Always	Sometimes	Sometimes
Macedonia	Sometimes	Always	Sometimes	Never	Sometimes
Malaysia			Always		Rarely
Malta			Always		
Mexico	Sometimes	Sometimes	Sometimes	Never	Rarely
Moldova	Rarely	Always	Sometimes		Sometimes
Mongolia	Always	Always	Rarely	Rarely	
Nepal	Always	Sometimes	Never	Rarely	Rarely
Netherlands	Never	Never	Always	Always	
New Zealand	Never	Never	Sometimes	Sometimes	Sometimes
Nicaragua	Always	Sometimes	Sometimes	Never	
Nigeria	Rarely	Rarely	Rarely	Rarely	Rarely
Norway	Never	Never	Always	Always	Sometimes
Pakistan	Sometimes	Sometimes	Rarely	Sometimes	Always
Palestine	Always	Rarely	Always	Sometimes	Rarely
Panama	Never	Rarely	Always	Rarely	Sometimes
Peru	Sometimes	Sometimes	Always	Never	Rarely
Philippines	Always	Always	Sometimes	Rarely	Never
Poland			Always	Never	Rarely
Portugal	Rarely	Rarely	Sometimes	Sometimes	Sometimes
Romania	Sometimes	Sometimes	Sometimes	Rarely	Rarely
Russia	Always	Always	Always	Sometimes	Rarely
Saudi Arabia	Never	Never	Always	Never	Sometimes
Senegal	Always	Always	Sometimes	Sometimes	Rarely
Serbia & Montenegro	Rarely	Rarely	Always	Never	Sometimes
Singapore	Never	Never	Always	Never	Never
Slovak Republic			Always		Rarely
Slovenia					
South Africa	Rarely	Rarely	Always	Sometimes	Rarely
Spain	Never	Never	Always	Always	Always
Sri Lanka	Always	Always	Sometimes	Rarely	Never
Sudan	Rarely	Rarely	Always	Rarely	Never
Sweden	Never	Never	Sometimes	Always	Sometimes
Switzerland			Sometimes	Sometimes	Rarely
Thailand	Always	Always	Sometimes	Rarely	Sometimes
Tunisia	Always	Always	Never	Never	







<b>Country</b>	<b>B17. Reported use: plasma</b>	<b>B18. Reported use: cryo</b>	<b>B19. Reported use: plasma-derived conc.</b>	<b>B20. Reported use: recombinant</b>	<b>B21. Reported use: DDAVP</b>
Ukraine	Sometimes	Sometimes	Rarely	Never	Rarely
United Kingdom	Never	Never	Rarely	Sometimes	Sometimes
United States	Rarely	Rarely	Sometimes	Always	Sometimes
Uruguay	Sometimes	Sometimes	Sometimes	Never	Rarely
Uzbekistan	Always	Always	Never	Never	Never
Venezuela			Always		Sometimes
Viet Nam	Always	Always	Sometimes	Rarely	Rarely
Zimbabwe			Sometimes		



## Healthcare System

Country	Population	C1. No. of HTCs	C2. No. of people cared for at HTCs	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Albania	3,130,000	1	100		no	
Algeria	32,854,000	14	977	Factor assay	no	no
Argentina	38,747,000	19	1,375	Factor assay	no	yes
Armenia	3,016,000	0		Clotting screening test	no	no
Australia	20,155,000	15	1,605	Factor assay	no	yes
Austria	8,189,000	20	250	Factor assay	no	yes
Azerbaijan	8,411,000	1	150	Factor assay	no	no
Bangladesh	141,822,000	3	304	Factor assay	no	no
Belarus	9,755,000			Clotting screening test	no	no
Belgium	10,419,000	10	1,200	Factor assay		
Belize	270,000	3	14	Factor assay		
Bolivia	9,182,000	1	14	Clotting screening test		
Bosnia-Herzegovina	3,907,000			Factor assay	no	no
Brazil	186,405,000	30	7,647	Factor assay	no	no
Bulgaria	7,726,000	6	500	Factor assay	no	yes
Canada	32,268,000	25	5,947	Factor assay	yes	yes
Chile	16,295,000			Factor assay		
China	1,315,844,000			Clotting screening test		
Colombia	45,600,000	8	1,200	Factor assay	no	no
Costa Rica	4,327,000	1	131	Factor assay	no	yes
Croatia	4,551,000	4		Factor assay	no	no
Cuba	11,269,000	1	359	Factor assay	no	no
Cyprus	835,000	1	64	Factor assay	no	no
Denmark	5,431,000	2	888	Factor assay	no	yes
Dominican Republic	8,895,000			Factor assay		
Ecuador	13,228,000	6	412	Factor assay	no	no
Egypt	74,033,000	10		Factor assay		
El Salvador	6,881,000	3	274	Factor assay	no	no
Eritrea	4,401,000	1	6	Clinical symptoms	no	no
Estonia	1,330,000	3	39	Factor assay		
Finland	5,249,000	1		Factor assay	no	no
France	60,496,000	40	4,018	Factor assay	no	yes
Georgia	4,474,000	3	242	Factor assay	no	no
Germany	82,689,000			Factor assay	no	yes
Greece	11,120,000	4	350	Factor assay	no	no
Guatemala	12,599,000	1			no	yes
Honduras	7,205,000	2	136	Factor assay	no	no
Hungary	10,098,000	59	3,061	Factor assay	yes	yes
Iceland	295,000	1	30	Factor assay	no	no
India	1,103,371,000	64		Clotting screening test	no	no



Country	Population	C1. No. of HTC's	C2. No. of people cared for at HTC's	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Indonesia	222,781,000	9	1,103	Clotting screening test	no	no
Iran	69,515,000	16		Factor assay	yes	yes
Iraq	28,807,000	1		Factor assay	no	no
Ireland	4,148,000	4	600	Factor assay	yes	yes
Israel	6,725,000	3	473	Factor assay	no	
Italy	58,093,000	47	5,000	Factor assay	yes	yes
Jamaica	2,651,000	3	109	Factor assay	no	yes
Japan	128,085,000	8		Factor assay	no	yes
Kenya	34,256,000	1	181	Clotting screening test	no	no
Korea	47,817,000	11		Factor assay	no	no
Kuwait	2,687,000			Factor assay	no	no
Latvia	2,307,000	2	110	Factor assay	no	no
Lebanon	3,577,000	4	110	Factor assay	no	no
Lithuania	3,431,000	2	100	Factor assay	no	no
Macedonia	2,034,000	1	200	Factor assay	no	no
Malaysia	25,347,000	36		Factor assay	no	no
Malta	402,000			Not known		
Mexico	107,029,000	7	2,110	Clotting screening test	no	no
Moldova	4,206,000			Factor assay	no	no
Mongolia	2,646,000	3	32	Factor assay	no	no
Nepal	27,133,000	1	200	Factor assay	no	
Netherlands	16,299,000	16	1,600	Factor assay	no	
New Zealand	4,028,000	6		Factor assay	yes	yes
Nicaragua	5,487,000	1	196	Clotting screening test		
Nigeria	131,530,000	0		Clinical symptoms		
Norway	4,620,000	1		Factor assay	yes	yes
Pakistan	157,935,000			Factor assay	no	no
Palestine	3,702,000	7	125	Factor assay	no	no
Panama	3,232,000	2		Factor assay	no	no
Peru	27,968,000	7	592	Clotting screening test	no	no
Philippines	83,054,000	1	62	Factor assay	no	no
Poland	38,530,000	32		Factor assay	no	no
Portugal	10,495,000	7		Factor assay	no	yes
Romania	21,711,000	9		Factor assay	no	no
Russia	143,202,000	4	1,800	Factor assay	no	no
Saudi Arabia	24,573,000	1	170	Factor assay	no	no
Senegal	11,658,000	1	108	Factor assay		no
Serbia & Montenegro	10,503,000	8	300	Factor assay		
Singapore	4,326,000			Factor assay		
Slovak Republic	5,401,000	44	380	Factor assay	no	
Slovenia	19,920,000	1	311	Factor assay		
South Africa	47,432,000	11		Factor assay	no	no





Country	Population	C1. No. of HTC's	C2. No. of people cared for at HTC's	C3. Diagnostic technique	C21. HCV compensation	C27. HIV compensation
Spain	43,064,000	34	2,891	Factor assay	yes	yes
Sri Lanka	20,743,000			Clinical symptoms	no	
Sudan	36,233,000	1	350	Factor assay	no	
Sweden	9,041,000	3		Factor assay	yes	yes
Switzerland	7,252,000	10	692	Factor assay	no	yes
Thailand	64,233,000	34	1,325	Factor assay	no	no
Tunisia	9,673,600	3		Factor assay		
Turkey	73,193,000	34	2,735	Factor assay	no	no
Ukraine	46,481,000	2		Factor assay	no	no
United Kingdom	59,668,000	92	2818	Factor assay	yes	yes
United States	298,213,000	135	27,662	Factor assay	no	yes
Uruguay	3,463,000	14	179	Factor assay	no	no
Uzbekistan	26,593,000	1	415	Clinical symptoms	no	no
Venezuela	26,749,000	5		Factor assay	no	no
Viet Nam	84,238,000	1	230	Factor assay	no	no
Zimbabwe	13,010,000			Factor assay		

### Reported Use of Factor Concentrates

Country	Data Year	Population	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
Albania	2005	3,130,000	800,000	100,000			20,000		800,000
Algeria	2004	32,854,000							
Argentina	2005	38,747,000							
Armenia	2004	3,016,000	30,000						30,000
Australia	2005	20,155,000	94,082,500	15,413,750	27,442,500	5,817,500	66,640,000	9,596,250	
Austria	2004	8,189,000							
Azerbaijan	2005	8,411,000	416,810						416,810
Bangladesh	2005	141,822,000	592,351	20,880	420,931	0	171,420	20,880	221,475
Belarus	2004	9,755,000	2,000,000	500,000	2,000,000	500,000			
Belgium	2003	10,419,000							
Belize	2004	270,000	70,000	120,000					20,000
Bolivia	2003	9,182,000							
Bosnia-Herzegovina	2004	3,907,000	300,000	100,000	300,000	100,000			
Brazil	2005	186,405,000	224,000,000	60,000,000	224,000,000	60,000,000			
Bulgaria	2005	7,726,000	10,200,000	300,000	10,000,000	300,000	200,000		
Canada	2005	32,268,000	134,482,000	36,431,000	4,281,000	4,285,000	130,201,000	32,146,000	
Chile	2003	16,295,000							
China	2004	1,315,844,000							
Colombia	2005	45,600,000	27,500,000	2,500,000	26,500,000	1,000,000	1,000,000	1,500,000	
Costa Rica	2005	4,327,000	6,063,750	3,055,500					
Croatia	2005	4,551,000	1,200,000	40,000			1,200,000	40,000	
Cuba	2005	11,269,000					81,340	12,000	81,340
Cyprus	2004	835,000							
Denmark	2005	5,431,000							
Dominican Republic	2003	8,895,000							
Ecuador	2005	13,228,000	508,513	52,970					
Egypt	2005	74,033,000							
El Salvador	2004	6,881,000							
Eritrea	2004	4,401,000	981,804						
Estonia	2003	1,330,000							
Finland	2005	5,249,000	23,330,500	2,819,750	16,059,250	1,096,500	7,271,250	1,723,250	
France	2005	60,496,000	400,000,000	61,000,000	80,000,000	29,000,000	320,000,000	32,000,000	
Georgia	2005	4,474,000	1,851,175	359,500	1,800,000	308,500			51,175
Germany	2005	82,689,000							
Greece	2005	11,120,000	28,400,769	4,494,960	4,484,854	187,750	23,915,915	4,307,210	
Guatemala	2005	12,599,000							
Honduras	2005	7,205,000	1,305,000						
Hungary	2005	10,098,000	51,300,000	4,500,000	49,800,000	4,500,000	1,500,000		
Iceland	2005	295,000	2,200,500	20,000	0	0	2,200,500	20,000	
India	2005	1,103,371,000	<b>16,859,668</b>	<b>2,050,551</b>					<b>12,906,168</b>
Indonesia	2005	222,781,000	2,458,500		2,174,060				681,036



Country	Data Year	Population	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
Iran	2005	69,515,000	100,000,000	20,000,000					
Iraq	2005	28,807,000							
Ireland	2005	4,148,000	16,075,250	7,667,500			16,075,250	7,667,500	
Israel	2005	6,725,000							
Italy	2005	58,093,000							
Jamaica	2004	2,651,000							
Japan	2005	128,085,000	291,349,000	39,700,000	116,083,000	39,700,000	175,266,000		
Kenya	2004	34,256,000	910,741	111,500					910,741
Korea	2005	47,817,000	82,429,500	13,121,250	55,614,000	1,890,250	26,815,500	11,231,000	
Kuwait	2005	2,687,000							
Latvia	2005	2,307,000	3,336,050	418,720	3,336,050	418,720			51,800
Lebanon	2004	3,577,000	2,348,420	729,600	1,408,000	729,600			868,420
Lithuania	2005	3,431,000							
Macedonia	2004	2,034,000	900,000	50,000	900,000	50,000			500,000
Malaysia	2005	25,347,000	10,491,740	6,268,910					
Malta	2003	402,000							
Mexico	2005	107,029,000	41,700,000	11,640,000	41,700,000	11,640,000			
Moldova	2005	4,206,000							108,000
Mongolia	2004	2,646,000	496,210				496,210		496,210
Nepal	2005	27,133,000	192,865	16,200					192,865
Netherlands	2005	16,299,000							
New Zealand	2005	4,028,000	19,219,000	3,320,250	6,332,000	2,329,000	12,887,000	991,250	
Nicaragua	2003	5,487,000							
Nigeria	2005	131,530,000	50,000				50,000		50,000
Norway	2005	4,620,000							
Pakistan	2005	157,935,000	1,367,900	22,046	412,954	21,536	954,946	510	954,946
Palestine	2004	3,702,000	1,470,500	42,480					
Panama	2005	3,232,000							
Peru	2005	27,968,000	4,500,000	1,000,000	4,500,000	1,000,000			
Philippines	2004	83,054,000	915,697		900,000				
Poland	2005	38,530,000	60,000,000	6,000,000	60,000,000	6,000,000			
Portugal	2005	10,495,000	31,764,750	4,999,500	15,858,000	4,564,000	15,906,750	435,500	
Romania	2005	21,711,000	1,700,000	300,000					500,000
Russia	2005	143,202,000	100,000,000	15,000,000	99,060,000	15,000,000	940,000		
Saudi Arabia	2004	24,573,000							
Senegal	2004	11,658,000							
Serbia and Montenegro	2005	10,503,000							
Singapore	2005	4,326,000							
Slovak Republic	2004	5,401,000	15,900,000	1,300,000	15,900,000	1,300,000			
Slovenia	2004	19,920,000							
South Africa	2005	47,432,000	29,500,000	3,700,000	29,500,000	3,700,000			
Spain	2005	43,064,000	90,000,000	16,500,000	37,000,000	11,500,000	52,000,000	5,000,000	
Sri Lanka	2004	20,743,000							





Country	Data Year	Population	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
Sudan	2005	36,233,000	2,190,000	360,000	2,000,000	360,000	190,000	0	190,000
Sweden	2005	9,041,000	61,249,000	12,598,000	6,026,000	7,993,000	55,223,000	4,605,000	
Switzerland	2005	7,252,000	25,752,250	5,007,100	8,659,250	495,900	17,023,000	4,547,600	
Thailand	2005	64,233,000							
Tunisia	2003	9,673,600							
Turkey	2005	73,193,000	50,000,000	10,000,000	50,000,000	10,000,000			
Ukraine	2005	46,481,000							30,000
United Kingdom	2005	59,668,000	253,275,120	46,026,311	71,050,647	19,930,911	182,224,473	26,095,400	
United States	2005	298,213,000							
Uruguay	2004	3,463,000	4,145,250	430,000	1,000,000				
Uzbekistan	2005	26,593,000							325,575
Venezuela	2005	26,749,000	22,334,971	8,231,140	12,025,260	3,079,800	1,462,500		
Viet Nam	2005	84,238,000							35,000
Zimbabwe	2004	13,010,000							
<b>TOTALS:</b>			2,356,498,054	428,439,368					20,421,561



### Factor Use Per Capita

Country	FVIII use per capita	FIX use per capita
Albania	0.26	0.03
Armenia	0.01	
Australia	4.67	0.76
Azerbaijan	0.05	
Bangladesh	0.00	0.00
Belarus	0.21	0.05
Belize	0.26	0.44
Bosnia-Herzegovina	0.08	0.03
Brazil	1.20	0.32
Bulgaria	1.32	0.04
Canada	4.17	1.13
Colombia	0.60	0.05
Costa Rica	1.40	0.71
Croatia	0.26	0.01
Ecuador	0.04	0.00
Eritrea	0.22	
Finland	4.44	0.54
France	6.61	1.01
Georgia	0.41	0.08
Greece	2.55	0.40
Honduras	0.18	
Hungary	5.08	0.45
Iceland	7.46	0.07
India	0.02	0.00
Indonesia	0.01	
Iran	1.44	0.29
Ireland	3.88	1.85
Japan	2.27	0.31
Kenya	0.03	0.00
Korea	1.72	0.27
Latvia	1.45	0.18
Lebanon	0.66	0.20
Macedonia	0.44	0.02
Malaysia	0.41	0.25
Mexico	0.39	0.11
Mongolia	0.19	
Nepal	0.01	0.00
New Zealand	4.77	0.82
Pakistan	0.01	0.00
Palestine	0.40	0.01
Peru	0.16	0.04
Philippines	0.01	
Poland	1.56	0.16
Portugal	3.03	0.48
Romania	0.08	0.01
Russia	0.70	0.10
Slovak Republic	2.94	0.24
South Africa	0.62	0.08
Spain	2.09	0.38
Sudan	0.06	0.01
Sweden	6.77	1.39
Switzerland	3.55	0.69
Turkey	0.68	0.14
United Kingdom	4.24	0.77
Uruguay	1.20	0.12
Venezuela	0.83	0.31



**Products Used****D4. Factor VIII Concentrates**

Brand Name	Manufacturer	Reported Use
Aafact	Sanquin, CLB	Finland, India, Netherlands
Advate	Baxter	France
AHF (High Purity)	CSL Ltd.	Israel, Malaysia, New Zealand
Alphanate	Grifols	India, Iraq, Italy, Peru, Switzerland, United Kingdom, United States
Amofil	Finnish Red Cross BTS	
Beriate P = Beriate HS	ZLB Behring	Italy, Mexico, Spain, Switzerland, Turkey, United Kingdom
Biostate (Factor VIII)	CSL Ltd.	Australia, Malaysia, New Zealand
Conco-eight-HT	Benesis	Japan
Confact F	Kaketsuken	Japan
Cross Eight M	Japanese Red Cross	Japan
Emoclot D.I.	Kedrion	Georgia, India, Italy, Portugal, Russia, Turkey
FACTANE	LFB	France, India, Iraq
Factor 8 Y	Bio Products Laboratory	Brazil, Colombia, Costa Rica, Greece, India, Iraq, Israel, Latvia, Sudan, Turkey, United Kingdom
Faktor VIII Intersero	Intersero	
Fanhdi	Grifols	Germany, Ireland, Italy, Peru, Poland, Spain, Turkey, United Kingdom
GreenEight	Greencross PD	Korea
GreenMono	Greencross PD	Korea
Haemate P = Haemate HS	ZLB Behring	Finland, Germany, Greece, Hungary, Iceland, India, Israel, Italy, Netherlands, Norway, Romania, Serbia, Spain, Sweden, Switzerland, Turkey, United Kingdom
Haemoctin SDH	Biotest	Germany, Hungary, India, Iran, Iraq, Kuwait, Russia
Haemosolvate Factor VIII	Natal Bioproducts Institute	Colombia, South Africa
Helixate FS = Helixate NexGen	ZLB Behring	France, Greece, Iceland, India, Ireland, Italy, Nepal, Netherlands, Nigeria, Norway, Portugal, Spain, Sweden, Switzerland, United Kingdom, United States
Hemofil M AHF	Baxter	Azerbaijan, Brazil, Bulgaria, Colombia, Croatia, Ecuador, Canada, Greece, Guatemala, Hungary, India, Iraq, Israel, Italy, Latvia, Lithuania, Malaysia, Mexico, Netherlands, Panama, Peru, Poland, Russia, Spain, Thailand, Turkey, United Kingdom, United States, Venezuela
HEMORAAS, SD plus H	Shanghai RAAS	Costa Rica, Georgia





Humate P	ZLB Behring	Canada, India, Israel, Portugal, United States
Immunate	Baxter Bioscience	Bulgaria, Croatia, Georgia, Germany, Hungary, India, Iran, Israel, Italy, Kuwait, Latvia, Lithuania, Netherlands, Poland, Romania, Russia, Serbia, Switzerland, Turkey, Ukraine, Venezuela
Koate DVI	Bayer	Bangladesh, Bulgaria, Georgia, Guatemala, Hungary, India, Indonesia, Iran, Israel, Malaysia, Pakistan, Panama, Russia, Turkey, Ukraine, United Kingdom, United States
Kogenate FS = Kogenate Bayer (in EU)	Bayer	Bulgaria, Canada, France, Germany, Greece, Honduras, Hungary, India, Iraq, Ireland, Israel, Japan, Nepal, Netherlands, New Zealand, Nigeria, Norway, Pakistan, Portugal, Russia, Spain, Sweden, Switzerland, United Kingdom, United States
Liberate HT	SNBTS	United Kingdom
Monarc-M	American Red Cross	Colombia, Germany, India, Israel, Panama, Turkey, United States, Venezuela
Monoclote P	ZLB Behring	Azerbaijan, Brazil, Cuba, Ecuador, France, Germany, India, Israel, Korea, United Kingdom, United States
Octanate	Octapharma	Croatia, Cuba, Georgia, Germany, Hungary, India, Iran, Mexico, Norway, Peru, Poland, Romania, Russia, Spain, Thailand, Turkey, Venezuela
Octonativ-M	Octapharma	Germany
Profilate	Grifols	Germany, Viet Nam
Recombinate	Baxter Bioscience	Australia, Colombia, Croatia, Canada, Finland, Germany, Iceland, India, Israel, Italy, Japan, Korea, Lithuania, Netherlands, New Zealand, Norway, Portugal, Russia, Spain, Switzerland, Turkey, United Kingdom, United States
ReFacto	Wyeth	Azerbaijan, Cuba, Finland, France, Germany, Greece, Israel, Italy, Netherlands, New Zealand, Norway, Pakistan, Portugal, Spain, Sweden, Switzerland, United Kingdom, United States
Replenate	Bio Products Laboratory	India, Israel, United Kingdom

**D5. Factor IX Concentrates**

<b>Brand Name</b>	<b>Manufacturer</b>	<b>Reported Use</b>
Aimafix	Kedrion	Georgia, India, Iran, Italy, Russia, Turkey, Venezuela
Alphanine SD	Grifols	India, Israel, Italy, Peru, Thailand, United Kingdom, United States, Viet Nam
BeneFIX	Wyeth	Australia, Colombia, Canada, India, Israel, Korea, New Zealand, United States
BeneFIX	Baxter SA	Finland, France, Germany, Greece, Iceland, Ireland, Italy, Netherlands, Portugal, Spain, Sweden, Switzerland, United Kingdom
Berinin-P = Berinin HS	ZLB Behring	Germany, Mexico, Switzerland, Turkey
BETAFACT	LFB	France, Greece, Iraq
HIP FIX	SNBTS	United Kingdom
Immunine	Baxter	Bulgaria, Colombia, Croatia, Canada, Georgia, Germany, Hungary, India, Italy, Kuwait, Latvia, Lithuania, Mexico, Nepal, Netherlands, Peru, Poland, Romania, Russia, Serbia, Spain, Switzerland, Turkey, Ukraine
Mono FIX-VF	CSL	Australia, New Zealand
Mononine	ZLB Behring	Ecuador, Canada, France, India, Israel, Italy, Pakistan, Spain, United States
Nanotiv	Octapharma	Croatia, Iran, Norway
Nonafact	Sanquin	Finland, Netherlands
Novact M	Kaketsuken	Japan
Octanine F	Octapharma	Cuba, Mexico, Russia, Thailand, Turkey
Octanyne	Octapharma	Brazil, Israel, Portugal, Turkey
Replenine – VF	Bio Products Laboratory	Brazil, Iraq, Israel, Latvia, Lithuania, Turkey, United Kingdom



**D6. Prothrombin Complex Concentrates**

<b>Brand Name</b>	<b>Manufacturer</b>	<b>Reported Use</b>
Bebulin VH	Baxter	India
Beriplex P/N	ZLB Behring	Brazil, Germany, Hungary, United Kingdom
Cofact (= PPSB in Belgium)	Sanquin	Finland
Facnyne	Greencross PD	Korea
Faktor IX HS	ZLB Behring	Israel, Spain
FEIBA VH	Baxter	Australia, Brazil, Croatia, Canada, France, Germany, Greece, Hungary, India, Iran, Ireland, Italy, Japan, Korea, Latvia, Lithuania, Mexico, Norway, Poland, Portugal, Romania, Russia, South Africa, Spain, Switzerland, Thailand, Turkey, United Kingdom, United States, Venezuela
Haemosolvex Factor IX	Natal Bioproducts Institute	South Africa
KASKADIL	LFB	Brazil, France
Profilnine SD	Grifols	Costa Rica, India, Malaysia, Thailand, United States
Proplex-T	Baxter	India, Israel, Japan, Malaysia, Panama, Peru
Prothoraas	Shanghai RAAS	Georgia
Prothrombinex- HT	CSL	Australia, Malaysia, New Zealand
PPSB-human SD/Nano 300/600	German Red Cross NSTOB	Germany
Prothromplex-T	Baxter	Brazil, Bulgaria, Croatia, Canada, Finland, Hungary, Iceland, India, Ireland, Italy, Panama, Peru, Poland, Switzerland, Venezuela
UMAN Complex D.I.	Kedrion	Italy, Russia

**D7. Other Products**

<b>Brand Name</b>	<b>Manufacturer</b>	<b>Reported Use</b>
Clottagen (fibrinogen)	LFB	France
FACTEUR VII	LFB	France, Israel
Factor VII	Baxter	Australia, Canada, Ireland, Lithuania, Russia, Switzerland, Venezuela
Factor XI	Bio Products Laboratory	Ireland, Israel, Sudan, United Kingdom
Fibrinogen	SNBTS	Canada, United Kingdom





Fibrogammin HS = Fibrogammin P (Factor XIII)	ZLB Behring	Croatia, Canada, Finland, France, Germany, Greece, Ireland, Israel, Lithuania, New Zealand, Poland, Serbia, Switzerland, United Kingdom
FIBRORAAS (fibrinogen)	Shanghai RAAS	
Haemocomplettan HS = Haemocomplettan P (fibrinogen)	ZLB Behring	Croatia, Finland, France, Germany, Hungary, Iran, Italy, Portugal, United Kingdom
HEMOLEVEN (Factor XI)	LFB	France, Israel, Spain
NovoSeven (Factor VIIa) = Niasstase (Canada)	NovoNordisk	Australia, Brazil, Bulgaria, Costa Rica, Croatia, Cuba, Canada, Finland, France, Greece, Hungary, Iceland, India, Iran, Iraq, Ireland, Israel, Italy, Japan, Korea, Kuwait, Latvia, Malaysia, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Romania, Russia, Serbia, South Africa, Spain, Switzerland, Thailand, Turkey, Ukraine, United Kingdom, United States, Venezuela
WILFACTIN	LFB	France, Greece



## Sample Survey Questionnaire

### A. National Hemophilia Organization

<b>A1.</b> Organization name	
<b>A2.</b> Address	
<b>A3.</b> City	
<b>A4.</b> State, Province, Region, Prefecture, County	
<b>A5.</b> Postal/ZIP Code	
<b>A6.</b> Country	
<b>A7.</b> Phone	
<b>A8.</b> Fax	
<b>A9.</b> E-mail	
<b>A10.</b> Website	

#### Executives of your association

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

<b>A15.</b> Number of full time staff working for the association	
<b>A16.</b> Number of active members in your hemophilia association/society	
<b>A17.</b> How many members in your association are medical doctors?	
<b>A18.</b> Does your association have an annual meeting?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>A19.</b> If yes, how many people attended this meeting?	
<b>A20.</b> 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
<b>B1.</b> Number of identified people with <b>hemophilia A and B</b> (PWH)		<input type="checkbox"/>
<b>B2.</b> Number of identified people with <b>von Willebrand disease</b> (vWD)		<input type="checkbox"/>
<b>B3.</b> Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		<input type="checkbox"/>

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



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

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

**Type of hereditary bleeding disorders**

Diagnosis	Number of persons
<b>B10.</b> Hemophilia A	
<b>B11.</b> Hemophilia B	
<b>B12.</b> Hemophilia, type unknown	
<b>B13.</b> von Willebrand disease	
<b>B14a.</b> Other hereditary bleeding disorders: Factor I deficiency	
<b>B14b.</b> Other hereditary bleeding disorders: Factor II deficiency	
<b>B14c.</b> Other hereditary bleeding disorders: Factor V deficiency	
<b>B14d.</b> Other hereditary bleeding disorders: Factor V+VIII deficiency	
<b>B14e.</b> Other hereditary bleeding disorders: Factor VII deficiency	
<b>B14f.</b> Other hereditary bleeding disorders: Factor X deficiency	
<b>B14g.</b> Other hereditary bleeding disorders: Factor XI deficiency	
<b>B14h.</b> Other hereditary bleeding disorders: Factor XIII deficiency	
<b>B14i.</b> Other hereditary bleeding disorders: platelet disorders	
<b>B14j.</b> Other hereditary bleeding disorders: type unknown	

**Number of identified people with hemophilia by diagnosis of severity**

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

**Products used to treat hemophilia**

<b>B17.</b> Plasma	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B18.</b> Cryoprecipitate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B19.</b> Plasma-derived concentrate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B20.</b> Recombinant	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B21.</b> DDAVP (Desmopressin)	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never

**Products used to treat vWD**

<b>B22.</b> Plasma	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B23.</b> Cryoprecipitate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B24.</b> Plasma-derived concentrate	<input type="checkbox"/> always	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	<input type="checkbox"/> never
<b>B25.</b> 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
<b>B26.</b> HIV		
<b>B27.</b> Hepatitis C		



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

Infectious Disease	Number of people tested	Number of people infected
<b>B28.</b> HIV		
<b>B29.</b> Hepatitis C		

**Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2004)**

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other inherited bleeding disorders
<b>B30.</b> Bleeding			
<b>B31.</b> HIV			
<b>B32.</b> Liver disease			
<b>B33.</b> Other causes			

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

<b>C1.</b> How many <b>hemophilia treatment centres</b> are there in your country?	
<b>C2.</b> Number of hemophilia patients regularly cared for by all these hemophilia treatment centres:	
<b>C3.</b> How are the majority of people with hemophilia diagnosed? ( <b>check one only</b> )	<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
<b>C4.</b> Who pays for the medical care for the majority of people with hemophilia? ( <b>check one only</b> )	<input type="checkbox"/> Government (social security, public healthcare system, etc.)
	<input type="checkbox"/> Private insurance
	<input type="checkbox"/> Patient
<b>C5.</b> Who pays for the medicine for the majority of people with hemophilia? ( <b>check one only</b> )	<input type="checkbox"/> Government (social security, public healthcare system etc.)
	<input type="checkbox"/> Private insurance
	<input type="checkbox"/> Patient

**Infectious diseases testing and vaccination**

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





<b>Hepatitis C</b>			
<b>C14.</b> Are more than 50% of people with hemophilia tested for hepatitis C?		<input type="checkbox"/>	<input type="checkbox"/>
<b>C15.</b> Are more than 50% of people with vWD tested for hepatitis C?		<input type="checkbox"/>	<input type="checkbox"/>

**Home Care**

<b>C16.</b> 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"/>
<b>C17.</b> What is the percentage of people 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**

<b>C18. Who pays for hemophilia treatment products in your country?</b>	<b>(Check any that apply)</b>	<b>If costs are shared, please indicate the percentage paid by each contributor</b>
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**

<b>C21.</b> Has there been compensation for HCV infection due to blood products in your country? <b>If YES, please answer the following questions:</b>	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
<b>C22.</b> Who paid the compensation?	Government	<input type="checkbox"/>
	Private companies	<input type="checkbox"/>
	Other	<input type="checkbox"/>
<b>C23.</b> How much was paid to each individual that was compensated?		
<b>C24.</b> What percentage of people with hemophilia infected with HCV were compensated?		



<b>C25.</b> How is the compensation paid?	One payment <input type="checkbox"/>	Other <input type="checkbox"/> (please describe)
<b>C26.</b> What years when patients were infected does the compensation apply to?	Start	Finish

#### Compensation for HIV infection

<b>C27.</b> Has there been compensation for HIV infection due to blood products in your country? <b>If YES, please answer the following questions:</b>	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
<b>C28.</b> Who paid the compensation?	Government	<input type="checkbox"/>
	Private companies	<input type="checkbox"/>
	Other	<input type="checkbox"/>
<b>C29.</b> How much was paid to each individual that was compensated?		
<b>C30.</b> What percentage of people with hemophilia infected with HIV were compensated?		
<b>C31.</b> How is the compensation paid?	One payment <input type="checkbox"/>	Other <input type="checkbox"/> (please describe)
<b>C32.</b> 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
<b>D1.</b> How many international units (IU) of <b>factor concentrates</b> were used in your country last year?			<input type="checkbox"/>
<b>D2.</b> How many international units of <b>plasma-derived</b> concentrates were used in your country last year?			<input type="checkbox"/>
<b>D3.</b> How many international units of <b>recombinant</b> concentrates were used in your country last year?			<input type="checkbox"/>
<b>D4.</b> How many international units were <b>humanitarian aid</b> ?			<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	ZLB 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"/>	Faktor VIII Intersero	Intersero	
<input type="checkbox"/>	Fanhdi	Grifols	
<input type="checkbox"/>	GreenEight	Greencross PD	
<input type="checkbox"/>	GreenMono	Greencross PD	
<input type="checkbox"/>	Haemate P = Haemate HS	ZLB Behring	
<input type="checkbox"/>	Haemoctin SDH	Biotest	
<input type="checkbox"/>	Haemosolvate Factor VIII	Natal Bioproducts Institute	
<input type="checkbox"/>	Helixate FS = Helixate NexGen	ZLB 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	ZLB Behring	
<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	ZLB Behring	
<input type="checkbox"/>	Octanate	Octapharma	
<input type="checkbox"/>	Octonativ-M	Octapharma	
<input type="checkbox"/>	Recombinat	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	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	ZLB 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	ZLB 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"/>	Bebulin VH	Baxter	
<input type="checkbox"/>	Beriplex P/N	ZLB Behring	
<input type="checkbox"/>	Cofact (= PPSB in Belgium)	Sanquin	
<input type="checkbox"/>	Facnyne	Greencross PD	
<input type="checkbox"/>	Faktor IX HS	ZLB Behring	
<input type="checkbox"/>	FEIBA VH	Baxter	
<input type="checkbox"/>	Haemosolvex Factor IX	Natal Bioproducts	
<input type="checkbox"/>	KASKADIL	LFB	
<input type="checkbox"/>	Profilnine SD	Alpha	
<input type="checkbox"/>	Proplex-T	Baxter	
<input type="checkbox"/>	Prothraas	Shanghai RAAS	
<input type="checkbox"/>	Prothrombinex- HT	CSL	
<input type="checkbox"/>	PPSB-human SD/Nano 300/600	German Red Cross 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"/>	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"/>	Fibrogammin HS = Fibrogammin P (Factor XIII)	ZLB Behring	
<input type="checkbox"/>	FIBRORAAS (fibrinogen)	Shanghai RAAS	
<input type="checkbox"/>	Haemocomplettan HS = Haemocomplettan P (fibrinogen)	ZLB Behring	
<input type="checkbox"/>	HEMOLEVEN (Factor XI)	LFB	
<input type="checkbox"/>	NovoSeven (Factor VIIa) = Niastase (Canada)	NovoNordisk	
<input type="checkbox"/>	WILFACTIN	LFB	



## Glossary

**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 treatment product independently at 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.



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