

Péče o děti s hemofilií v ČR

Data registru ČNHP

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Za centra zastoupená v ČNHP

System péče v ČR

- Český národní hemofilický program (ČNHP)
 - www.cnhp.cz
- Ročně se jedná o cca $\frac{3}{4}$ mld Kč pro cca 1000 lidí
- System center (2 úrovně)
 - 4 Komplexní (CCC): 2xFN Brno, FN Motol a ÚHKT
 - 7 Léčebných (HTC): Ostrava, Hradec Králové, Olomouc, Plzeň, Ústí n L., Č. Budějovice, Liberec
- Zásadní odlišnost center:
 - Ortopedie/chirurgie (vč. elektivní), inhibitory – CCC

Úhrada péče o hemofilii v ČR (2013)

- V rámci DRG ALFA (většina diagnóz/výkonů)
 - Hrazeno plně bez omezení
 - Chir/Int. dg HLAVNÍ, Hemofilie VEDLEJŠÍ !
- V rámci DRG BETA/GAMA
 - Hrazeno plně do výše stropu (výjimečně na chir. prac.)
- MIMO ÚV (tzv. “balíčky”, např TEP)
 - Individuální jednání ZZ a ZP
 - Snaha od r 2014 eliminovat tento způsob úhrady (?)

Úspěchy ČNHP

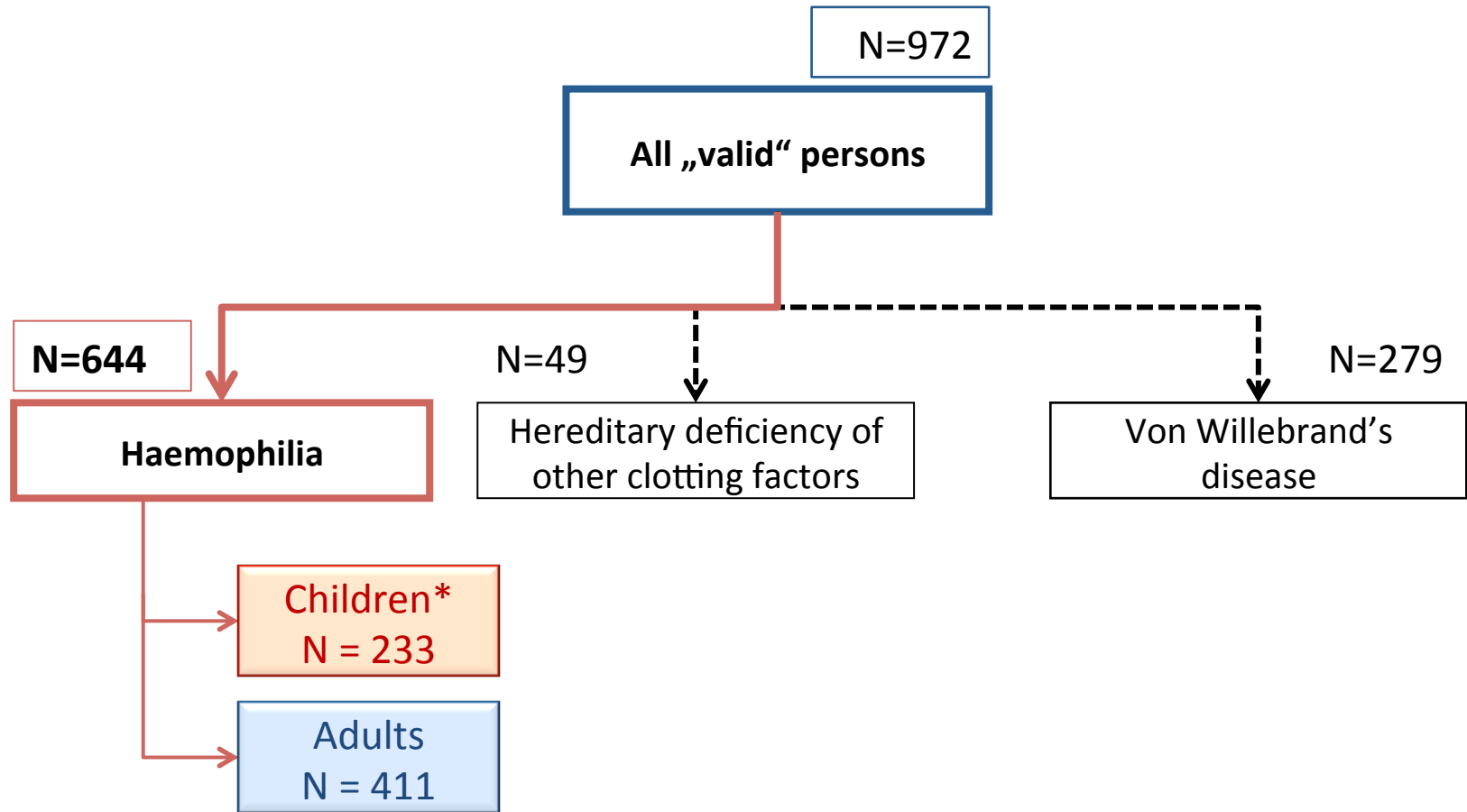
- Vytvoření formální sítě center a jejich akreditace za účasti odborné veřejnosti a VZP
 - První audit 2011
 - Re-audit vždy á 2 roky (věstník MZd)
- Úspěšné jednání S NRC a MZd směřující k vynětí úhrady léčby hemofilie z DRG a z “paušálů”
- Úzká spolupráce v rámci projektů Evropské komise EUHASS, EUHANET a stím související pozitivní “PR” české hemofilické péče

The current status of care for persons with haemophilia and von Willebrand's disease registered within CNHP registry

Jan Blatný, Petra Ovesná, Petr Brabec
on behalf of

Centres contributing to common database
of the CNHP (Czech National Haemophilia Programme)

Sample size



* Persons under 19 years old in 2012

Participating centres in CNHP

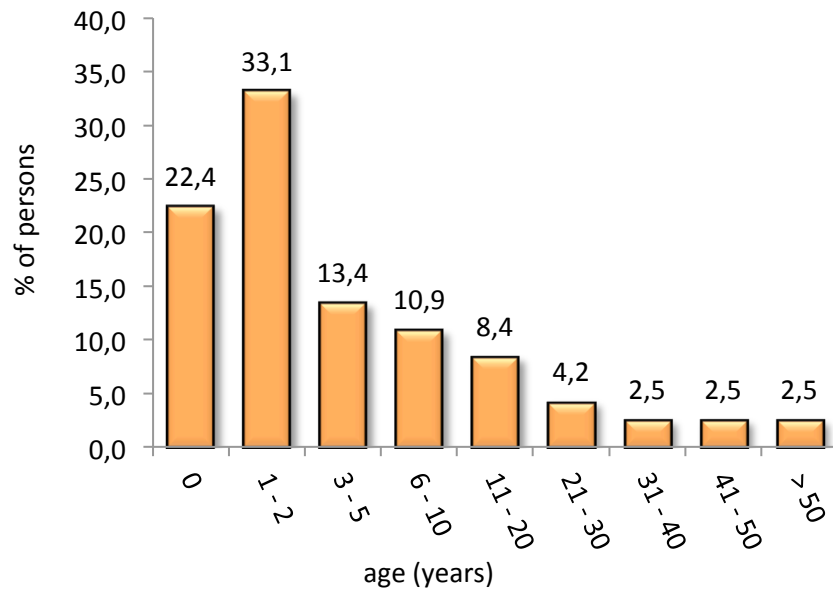
Paediatric centres	Valid persons	
	N	%
FN Motol – Dpt. of Pediatric Haematology and Oncology	86	13.4
FN Brno – DN – Dpt. of Pediatric Haematology	46	7.1
FNHK – Dpt. of Pediatric Medicine	35	5.4
UnL – Pediatric Dpt. – Haematology	29	4.5
FN Ostrava – Dpt. of Pediatric Medicine	29	4.5
FN Olomouc – Dpt. of Pediatric Medicine	11	1.7
FN Plzen – Pediatric Dpt.	10	1.6
CB – Pediatric Dpt.	9	1.4

Adult centres	Valid persons	
	N	%
FN Brno – OKH	124	19.3
FN Ostrava – Blood centre	74	11.5
FN Olomouc – Haemato-Oncology Dpt.	57	8.9
FN Plzen – UKBH	38	5.9
CB – OKH	26	4.0
FNHK – OKH	22	3.4
KN Liberec – OKH	20	3.1
UnL – OKH	8	1.2
Plzen – Health Centre – Haematology	7	1.1
UHKT Praha	6	0.9
Kolin – Haematology and Transfusion Dpt.	5	0.8
Pelhrimov - OHT	2	0.3

Age

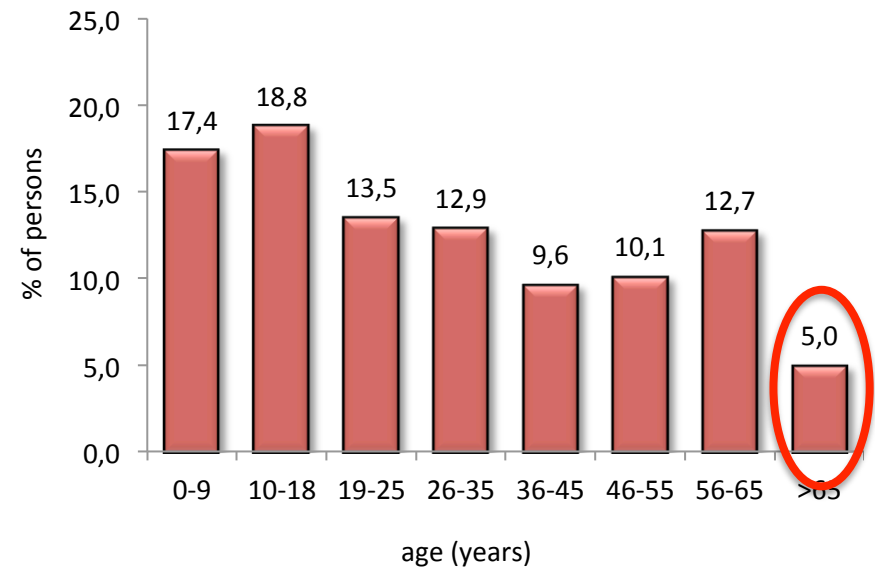
All
N=644

	Age at diagnosis (years)
N	477*
Mean	7.6
Median (min - max)	2 (0 – 69)



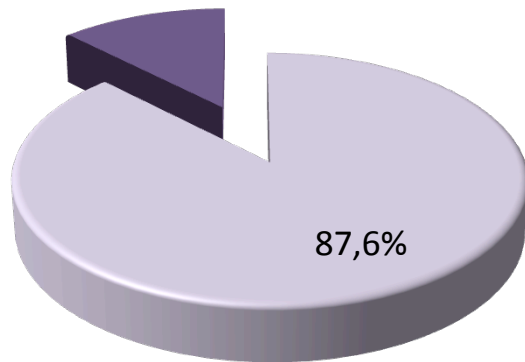
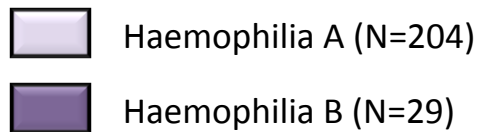
* Missing information on year of diagnosis in 167 persons.

	Current age (years)
N	644
Mean	30.5
Median (min - max)	26 (0 – 90)

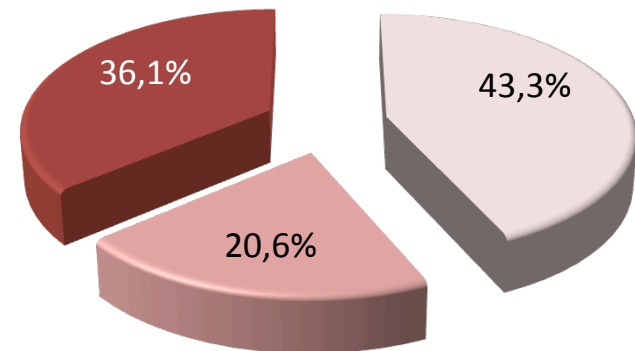
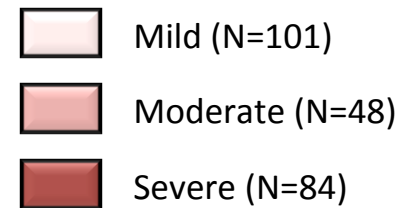


Type and severity of haemophilia I

Type of haemophilia



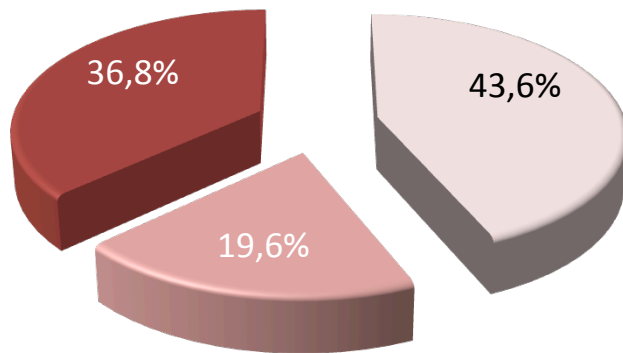
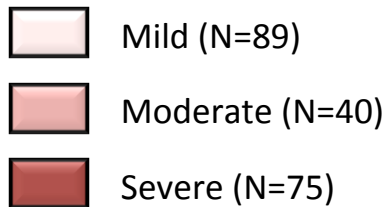
Severity of haemophilia (N=216)



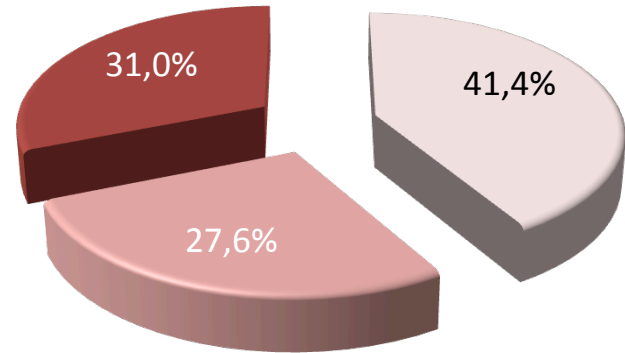
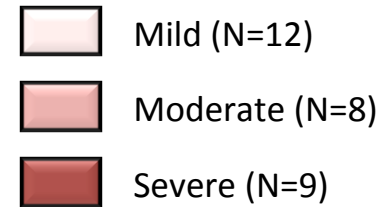
Type and severity of haemophilia II

Children
N=233

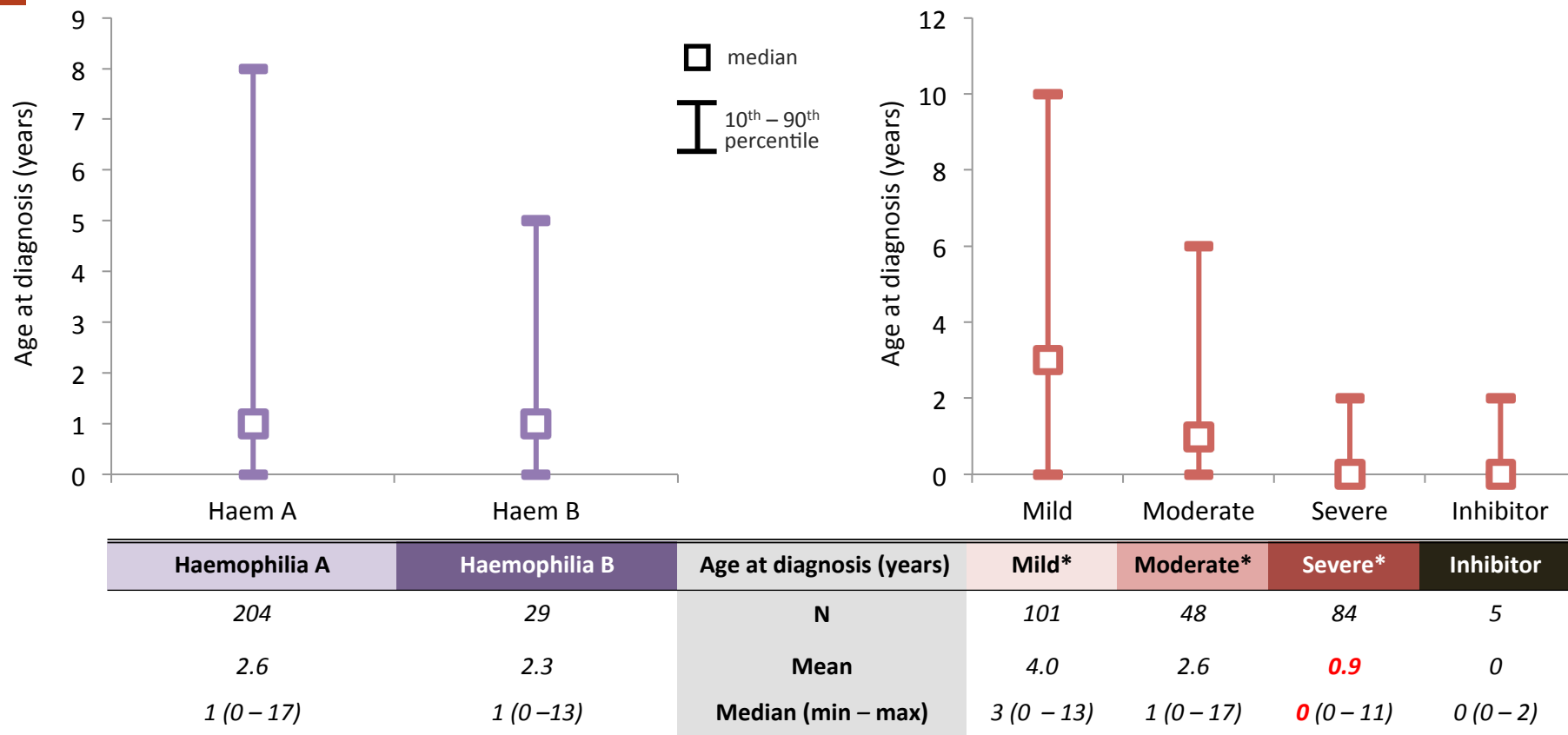
Haemophilia A (N=204)



Haemophilia B (N=29)



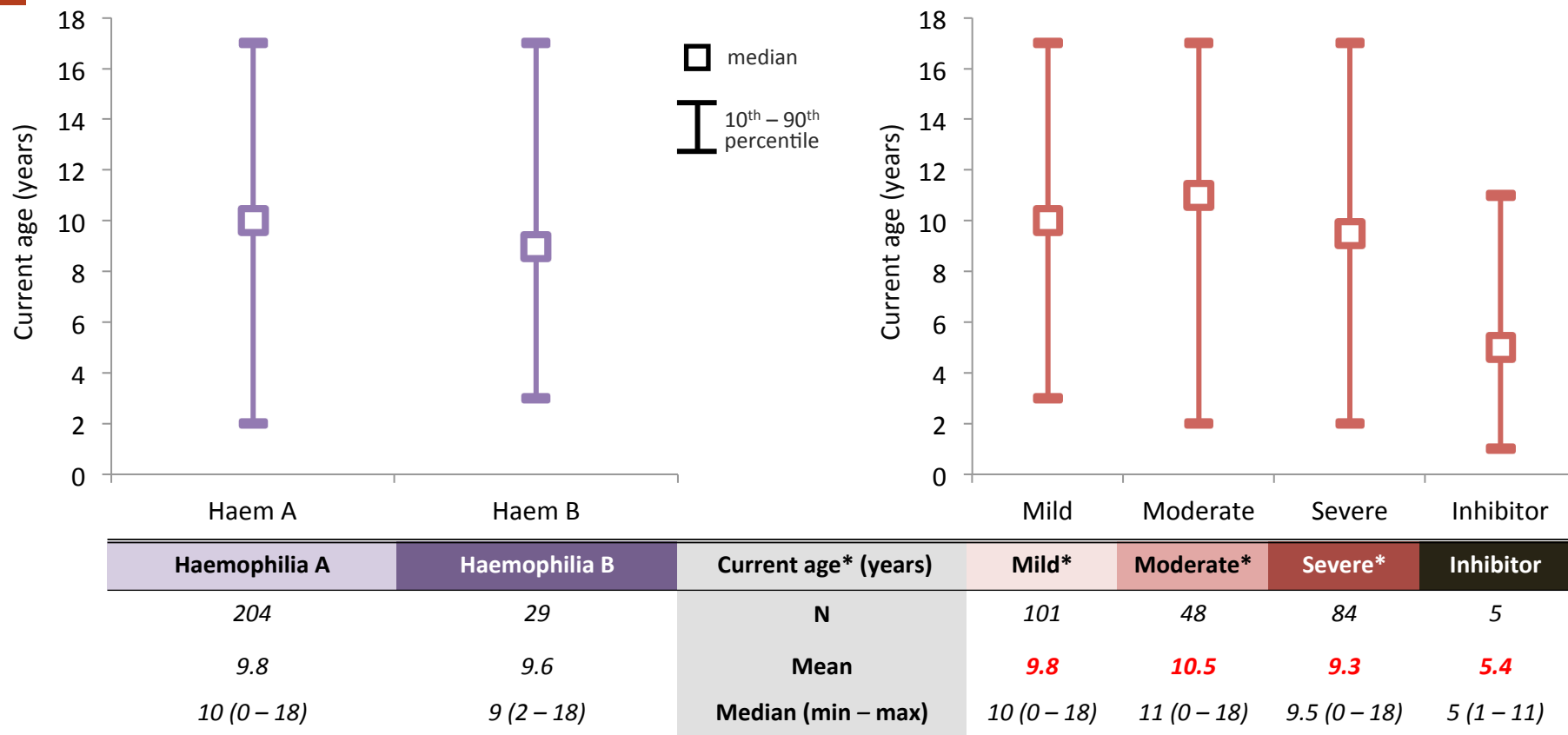
Age at diagnosis according to type and severity of haemophilia



* including persons with inhibitor

Actual age according to type and severity of haemophilia

Children
N=233

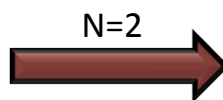
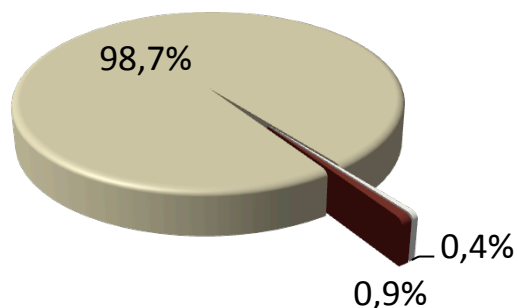
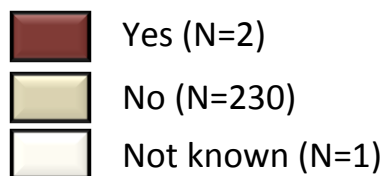


*Current age = age reached in year 2012

* including persons with inhibitor

Hepatitis experienced

Experienced hepatitis



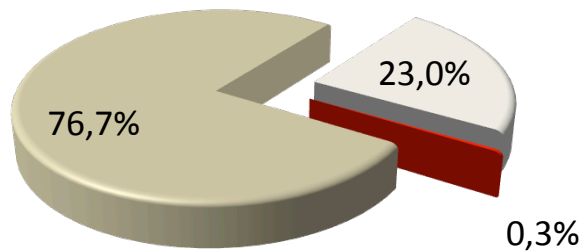
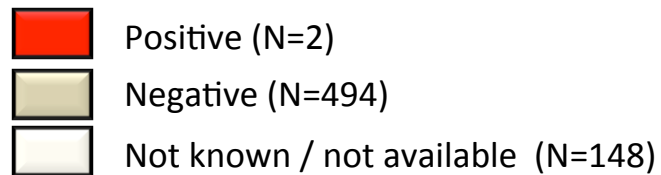
One child has hepatitis C, type of hepatitis not specified in one child.

Data from last annual report of each person.

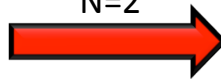
HIV

All
N=644

HIV



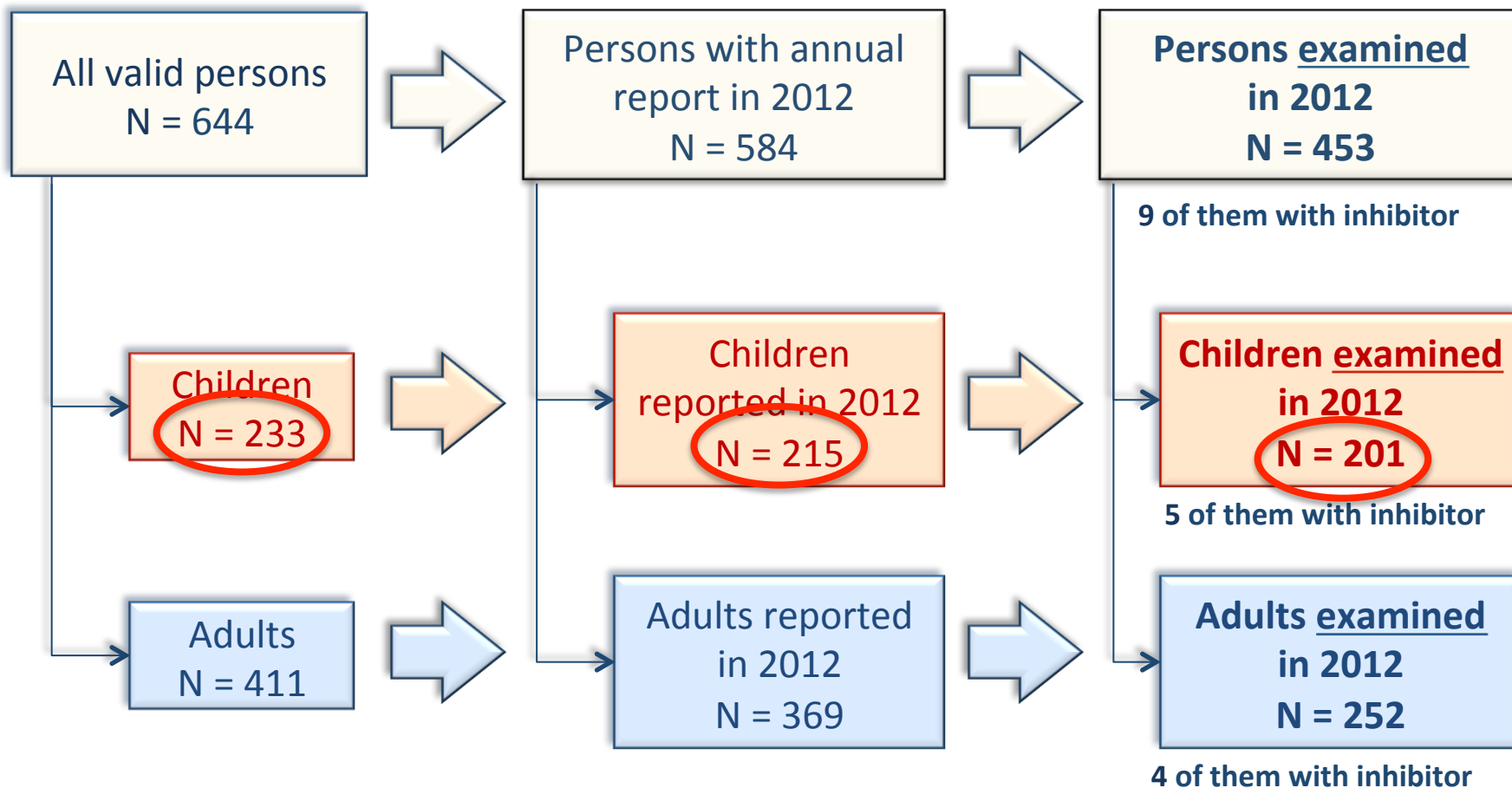
N=2



Both HIV-positive persons are adults.

Data from last annual report of each person.

Data from year 2012 – sample size



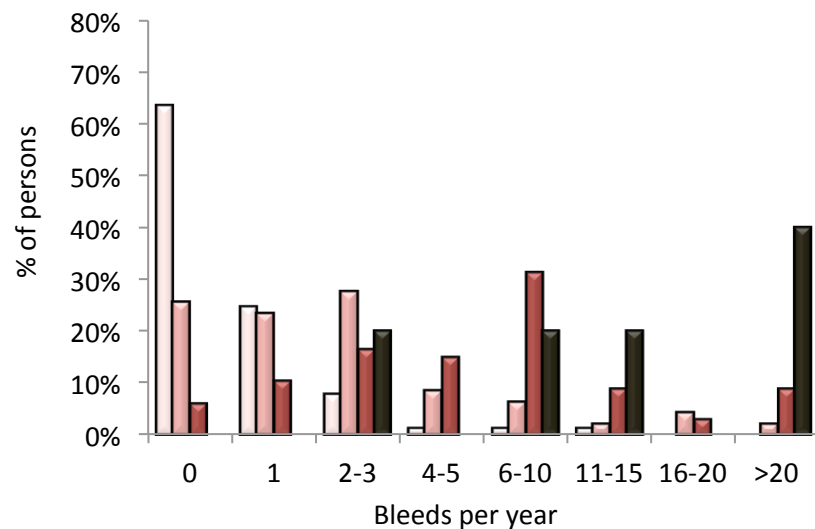
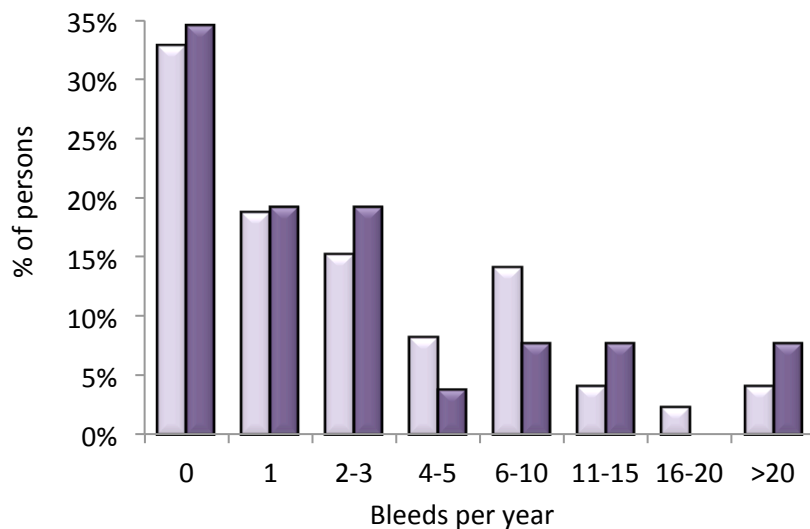
Persons with haemophilia with inhibitor

- inhibitor was recorded in 8 persons in year 2012
- other 1 person has recorded inhibitor in 2011 (data from 2012 are not available)



**currently 9 persons with inhibitor
(5 children and 4 adults) + 6 in other centre**

Frequency of bleeding requiring treatment in 2012



Haemophilia A	Haemophilia B	Frequency of bleeding	Mild*	Moderate*	Severe*	Inhibitor
175	26	N total	79	47	70	5
170	26	N valid	77	47	67	5
4.3	4.4	Mean	0.8	3.6	8.0 / 6.1[†]	15.2
1 (0 – 49)	1 (0 – 26)	Median (min – max)	0 (0 – 12)	2 (0 – 30)	6 / 5 (0 – 49)	11 (3 – 32)

* without inhibitor

[†] mean and median of frequency of bleeding in children with severe haemophilia without inhibitor on permanent prophylaxis

Frequency of bleeding is missing in 19 children.

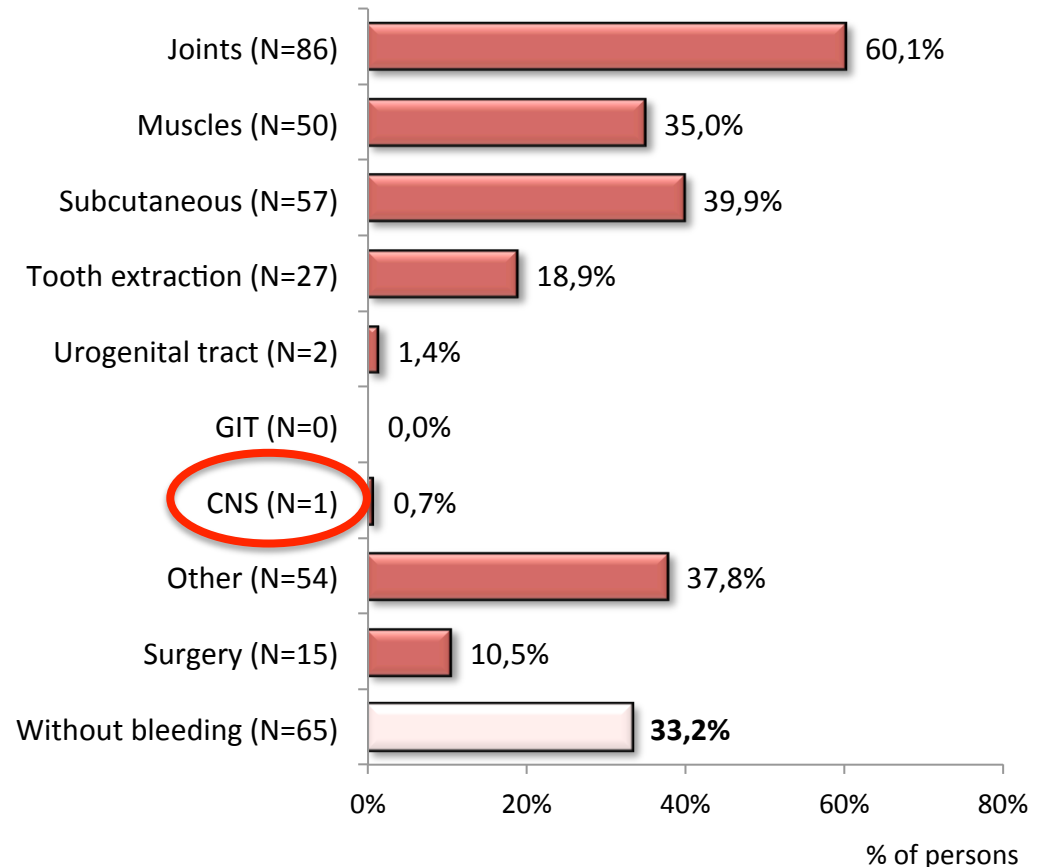
Location of (any) bleeds in 2012

131 (66.8%) children experienced bleeding requiring treatment at least once in year; 840 bleeds were recorded in total, 50 bleeds required hospitalization.

65 (33.2%) children recorded no bleed during year 2012.

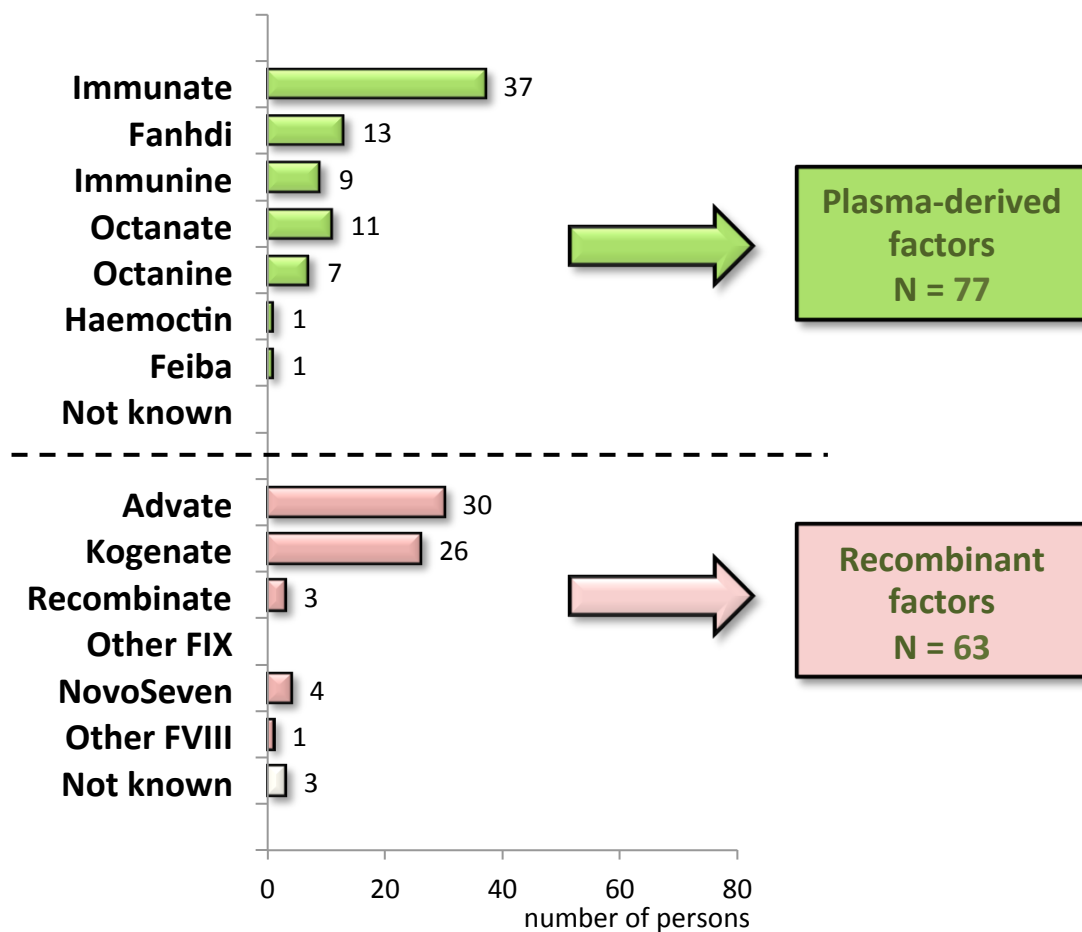
Information on frequency of bleeding is missing in 5 examined children.

Overall 143 persons have recorded location of any bleeds*.



* all recorded bleeds, regardless of requirement of treatment

Treatment

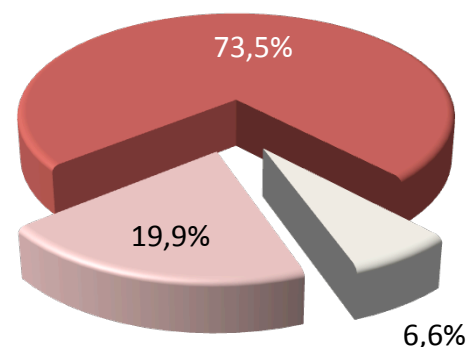
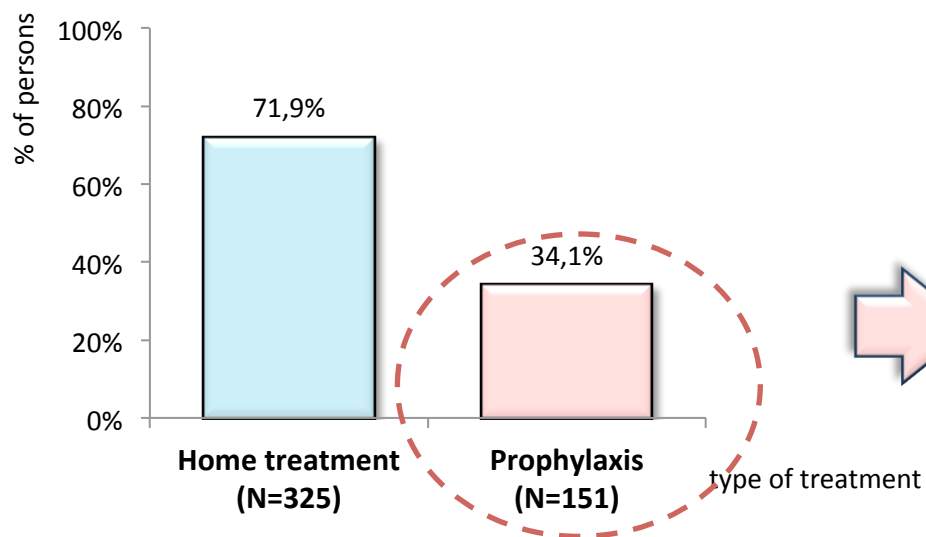


135 (67.2%) children received drugs in 2012 (11 of them more different drugs).

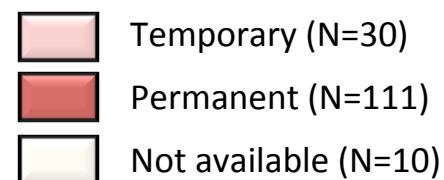
Plasma-derived factors were administered in 77 (38.3%) children, recombinant factors in 63 (31.3%).

Five children were treated with both plasma-derived and recombinant factor.

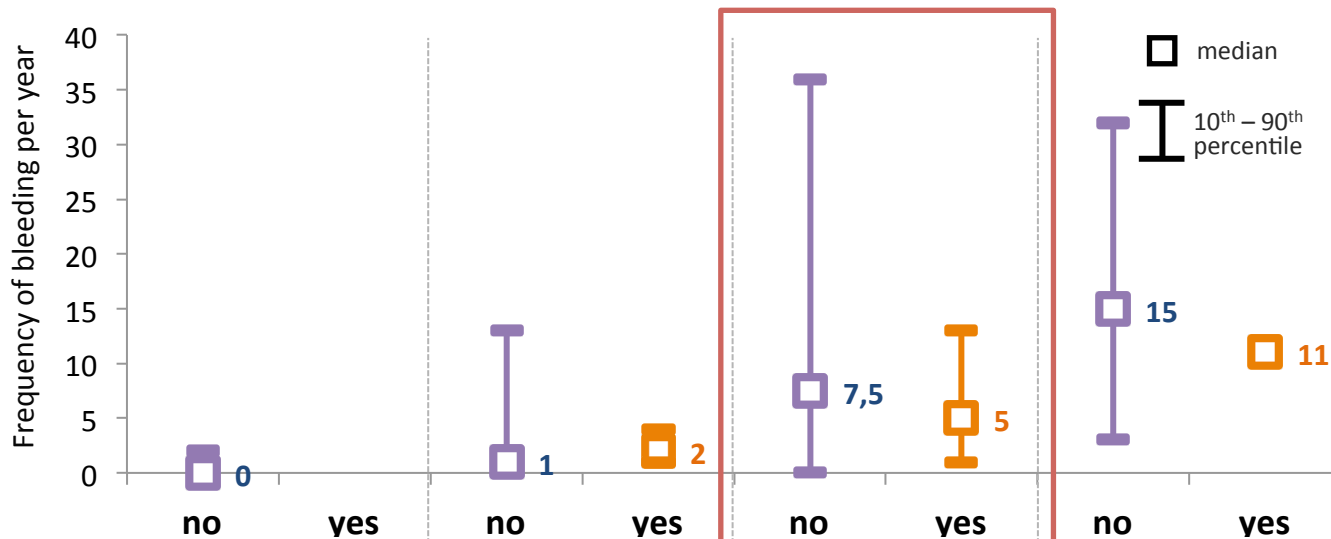
Type of treatment



Type of prophylaxis (N=151)



Bleeding requiring treatment according to prophylaxis



permanent prophylaxis

Frequency of bleeding	Mild*		Moderate*		Severe*		Inhibitor	
N	77		38	9	18	49	4	1
Mean	0.8		3.9	2.2	13.2	6.1	16.3	11.0
Median (min – max)	0 (0 – 12)		1 (0 – 30)	2 (1 – 4)	7.5 (0 – 49)	5 (0 – 25)	15 (3 – 32)	11
children on permanent prophylaxis	0 (0%)		9 (19.1%)		51 (72.9%)		1 (20%)	
% of drugs (FVIII and FIX) consumed by children on permanent prophylaxis	0 %		9 %		70 %		4 %	

* without inhibitor

Bleeding requiring treatment according to centres



Frequency of bleeding in children with haemophilia (A and B)
without inhibitor on **permanent prophylaxis**

Child centres	0	2	4	6	8	N	Mean	Median	Min	Max	Severity
FN Motol – Dpt. of Pediatric Haematology and Oncology						2	4.5	4.5	3	6	Moderate
						30	7.6	6.0	0	31	Severe
FN Brno – DN – Dpt. of Pediatric Haematology						1	5.0	5.0			Moderate
						12	5.3	5.0	0	13	Severe
FNHK – Dpt. of Pediatric Medicine						3	1.3	1.0	1	2	Moderate
						5	5.6	2.0	0	21	Severe
UnL – Pediatric Dpt. – Haematology						2	1.5	1.5	1	2	Severe
FN Ostrava – Dpt. of Pediatric Medicine						1	2.0	2.0			Moderate
						5	6.6	4.0	1	20	Severe
FN Olomouc – Dpt. of Pediatric Medicine						1	3.0	3.0			Moderate
FN Plzen – Pediatric Dpt.						1	5.0	5.0			Severe
CB – Pediatric Dpt.						3	2.7	2.0	2	4	Moderate
						2	2.0	2.0	1	3	Severe

Bleeding requiring treatment according to centres



Frequency of bleeding in children with haemophilia (A and B)
without inhibitor **regardless of prophylaxis**

Child centres	0	2	4	6	8	N	Mean	Median	Min	Max	% on premanent prophylaxis
FN Motol – Dpt. of Pediatric Haematology and Oncology	3,0					16	6.1	3.0	0	30	12.5
	7,0					41	8.9	7.0	0	31	73.2
FN Brno – DN – Dpt. of Pediatric Haematology	1,0					8	1.3	1.0	0	5	12.5
	5,0					15	6.0	5.0	0	14	80.0
FNHK – Dpt. of Pediatric Medicine	2,0					9	1.8	2.0	0	3	33.3
	2,0					5	5.6	2.0	0	21	100.0
UnL – Pediatric Dpt. – Haematology	0,0					2	0.0	0.0	0	0	0.0
	1,0					3	1.3	1.0	1	2	66.7
FN Ostrava – Dpt. of Pediatric Medicine	2,0					9	4.8	2.0	0	19	11.1
	5,0					8	11.5	5.0	0	36	62.5
FN Olomouc – Dpt. of Pediatric Medicine	1,0					3	1.3	1.0	0	3	33.3
FN Plzen – Pediatric Dpt.	5,5					4	15.3	5.5	1	49	25.0
CB – Pediatric Dpt.	2,0					3	2.7	2.0	2	4	100.0
	3,0					3	3.3	3.0	1	6	66.7

Consumption of drugs

Drug		Total annual consumption	Number of <u>treated</u> persons	Average annual consumption per <u>treated</u> child	Number of <u>examined</u> children	Average annual consumption per <u>examined</u> child
FVIII	Immunate	2 000 250 IU	37	54 060.8 IU	175	11 430.0 IU
	Fanhdi	1 099 750 IU	13	84 596.2 IU		6 284.3 IU
	Octanate	1 222 500 IU	11	111 136.4 IU		6 985.7 IU
	Haemoctin	163 500 IU	1	163 500.0 IU		934.3 IU
	Advate	1 775 712 IU	30	59 190.4 IU		10 146.9 IU
	Kogenate	1 853 825 IU	26	71 301.0 IU		10 593.3 IU
	Recombinate	464 000 IU	3	154 666.7 IU		2 651.4 IU
	Other recombinant	290 500 IU	4	72 625.0 IU		1 660.0 IU
	FVIII celkem	8 870 037 IU	117	75 812.3 IU		50 685.9 IU
FIX	Immunine	517 200 IU	9	57 466.7 IU	26	19 892.3 IU
	Octanine	273 500 IU	7	39 071.4 IU		10 519.2 IU
	Other plasma-derived					
	Other recombinant					
	FIX celkem	790 700 IU	15	52 713.3 IU		30 411.5 IU
aPCC	Feiba	60 000 IU	1	60 000.0 IU		
rFVIIa	NovoSeven	629 mg	4	157.3 mg		
Plasma-derived factors - TOTAL *		5 336 700 IU	77	69 307.8 IU	201	26 252.2 IU
Recombinant factors - TOTAL *		4 384 037 IU	60	73 067.3 IU		21 811.1 IU
TOTAL CONSUMPTION *		9 720 737 IU	133	73 088.2 IU		48 361.9 IU

•plasma-derived factors = Immunate, Fanhdi, Octanate, Immunine, Octanine, Other plasma-derived

•recombinant factors = Advate, Kogenate, Recombinate, BAX 326, Other recombinant

*TOTAL CONSUMPTION = all mentioned drugs excluding Feiba and NovoSeven

