National Haemophilia Database UK Statistics for 2006.

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Principal New Registrations:

Diagnosis	in 2006	Total in register
Haemophilia A	142	6388
Haemophilia B	22	1341
Von Willebrands dis.	300	8796
Factor XI	101	1696
Acqd. Haemophilia A	41	
Platelet defects	73	738
Total	872	23,672

Map 1: Haemophilia A & B Factor Usage (inc. inhibitors): by post code area.

This reflects uneven population density and uneven distribution of patients with haemophilia causing considerable variation in the cost per PCT for haemophilia Care

Map 2: Factor usage for haemophilia A & B (inc. inhibitors) for London and SE England.

This shows uneven usage even in areas of high population density due to clustering of patients.

Map 3: factor usage for haemophilia A &B (inc. inhibitors) per capita of population by post code.

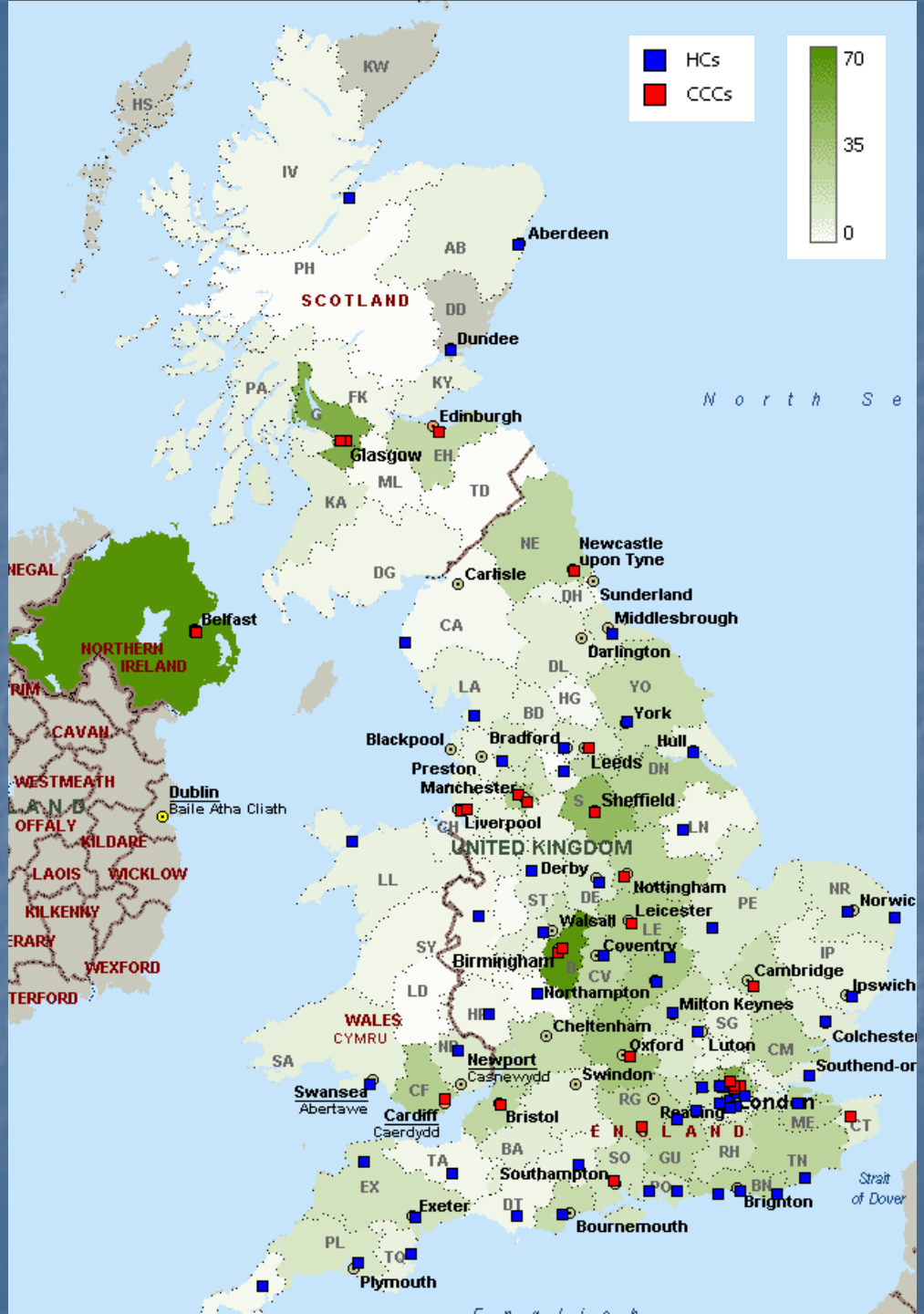
This shows uneven distribution of patients with Haemophilia because this presentation corrects for population density..

If prevalence of haemophilia were constant, there would be little geographic variation in usage per capita.

Mean 6.6 IU per capita,
Range 1.0-9.5 IU per capita.

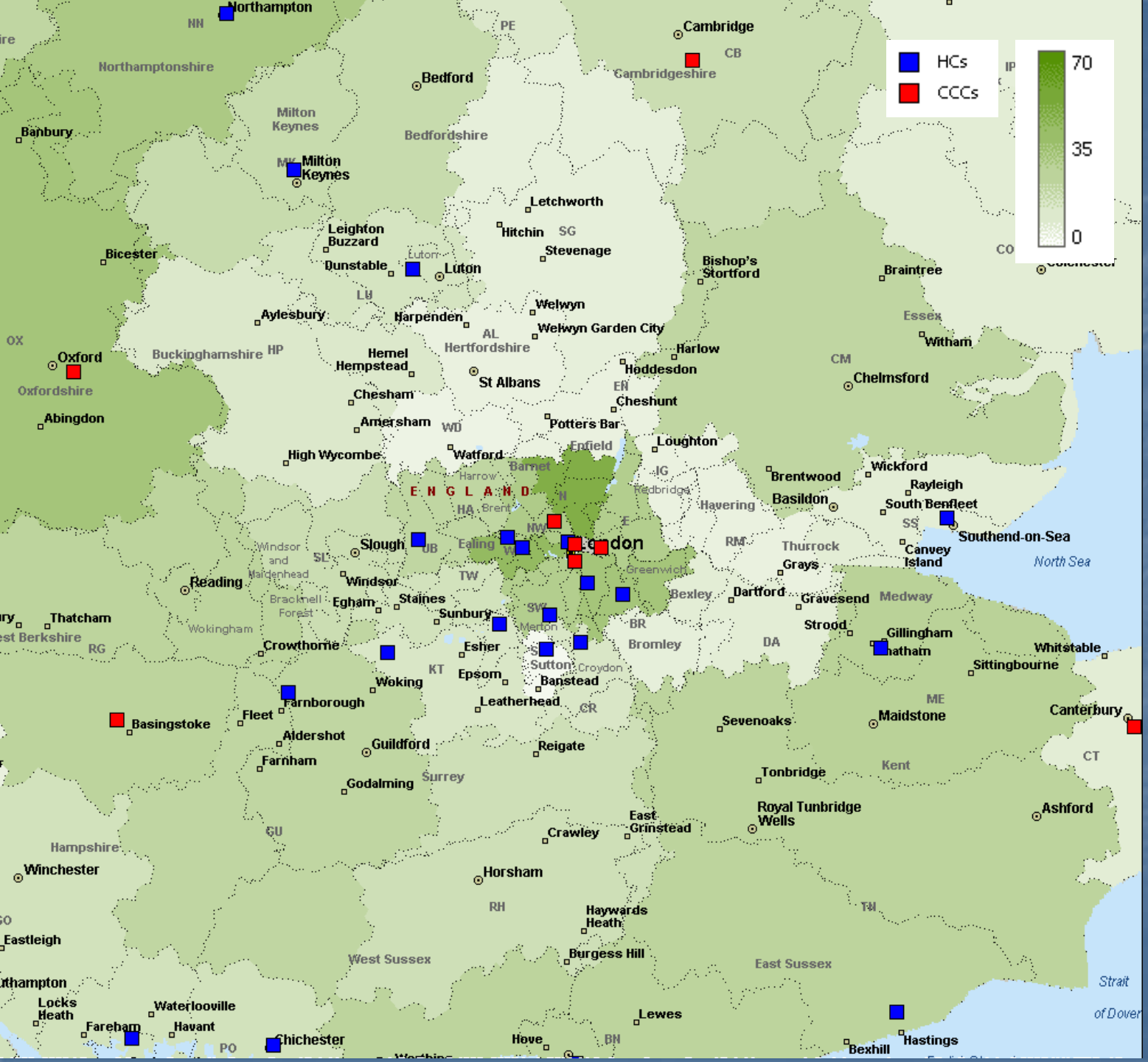
Map 4: Factor useage for Haemophilia A & B, per capita by postcode for London and SE England.

As before, this analysis, corrected for population density reflects the variable prevalence of haemophilia.



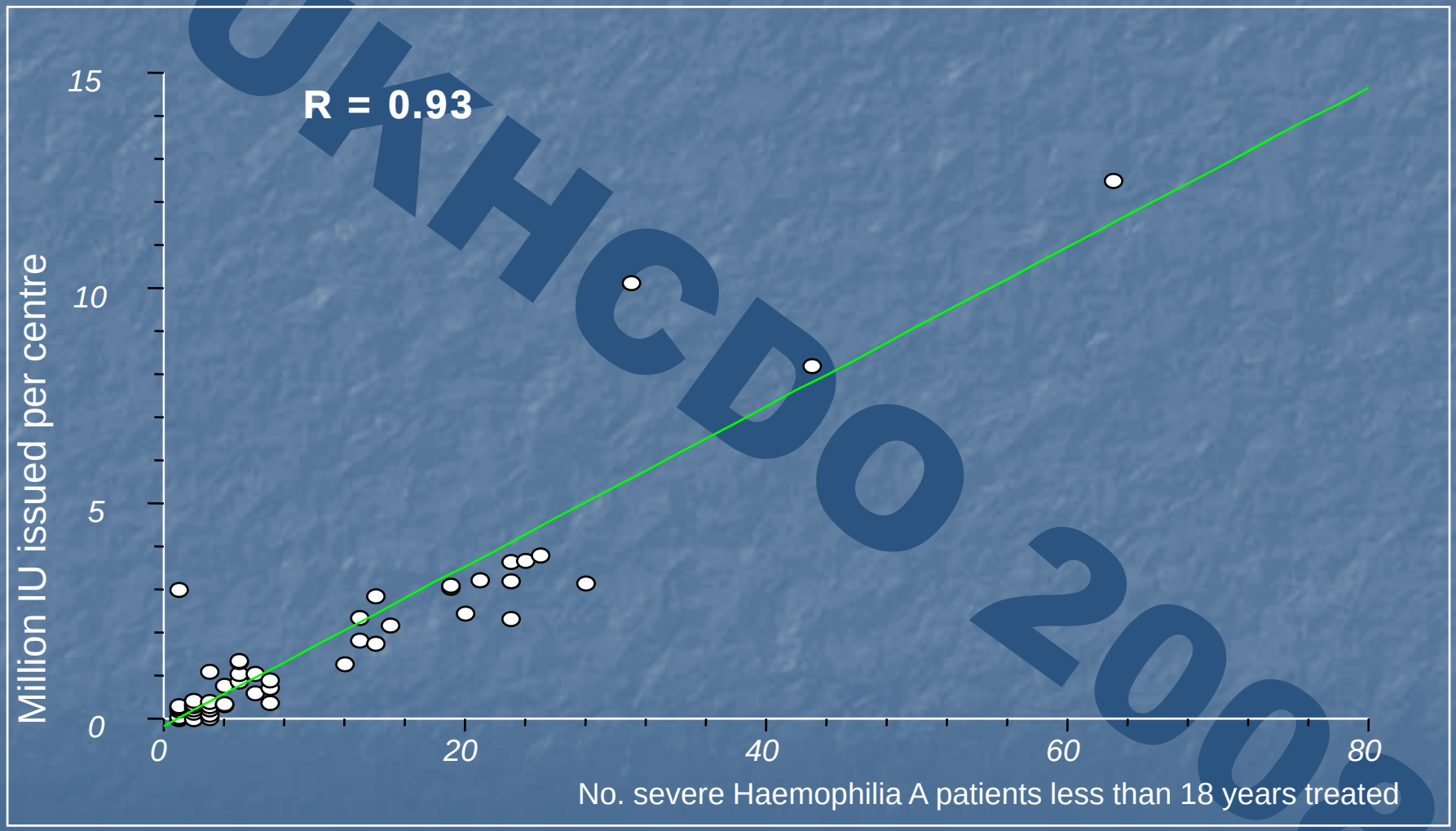
Map 5: Prevalence of haemophilia A & B by Postcode.

This shows clustering of patients unrelated to population density.

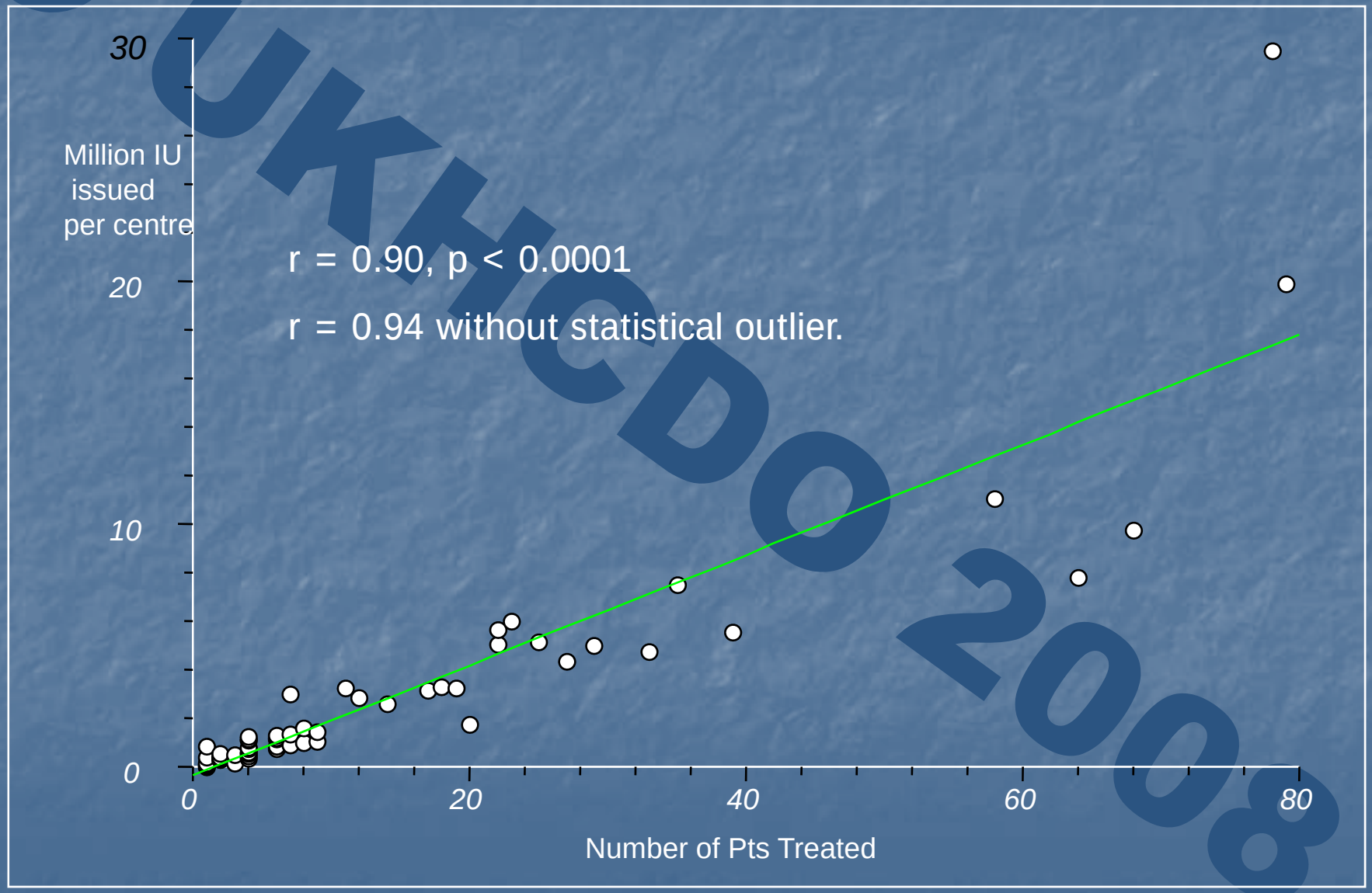


Map 6: Prevalence of Haemophilia A & B in London and SE England by postcode.

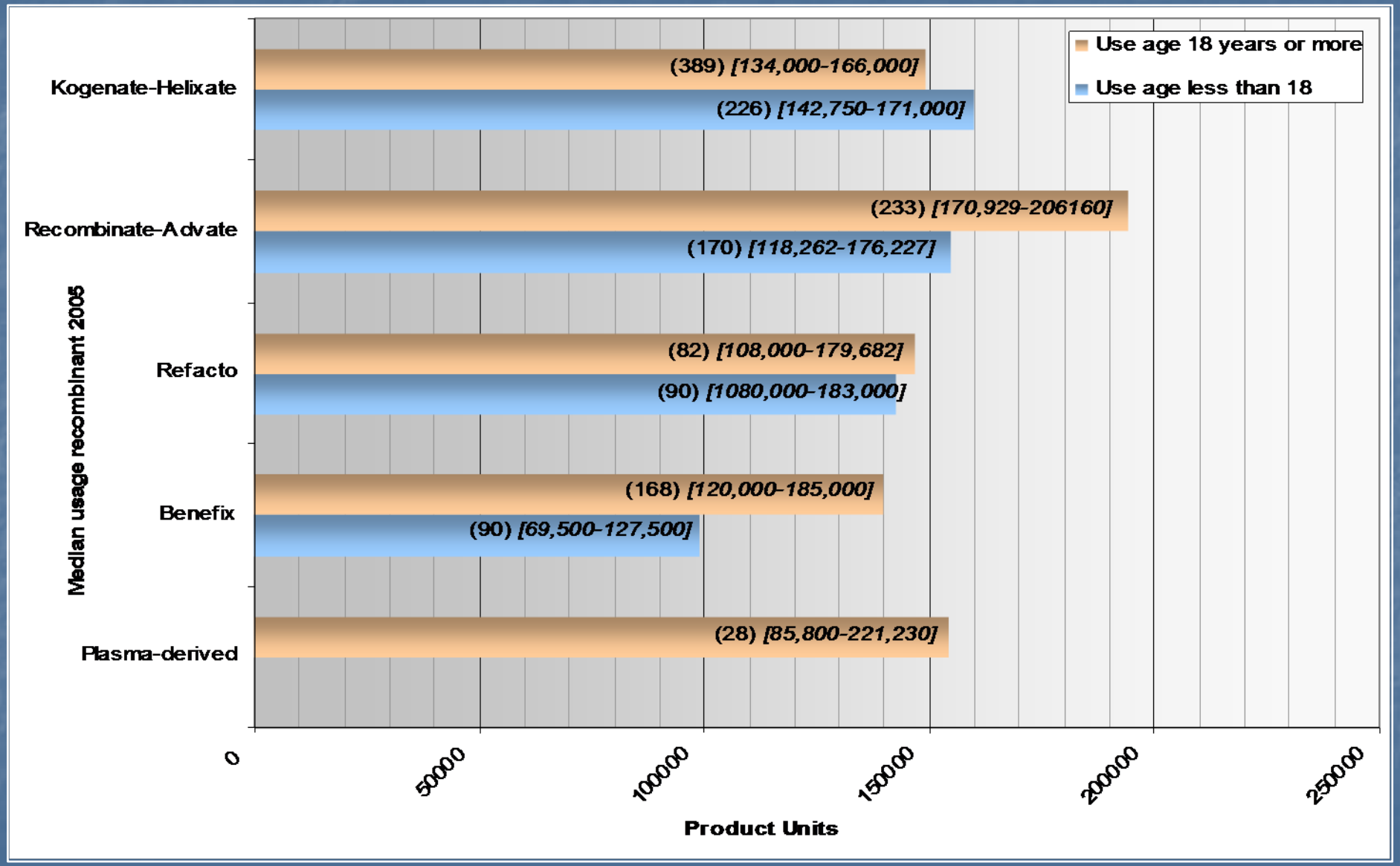
Factor VIII used per centre by number of pts < 18yrs without inhibitors treated: 2006.



Factor VIII use per centre for patients with haemophilia A > 18 yrs without inhibitor

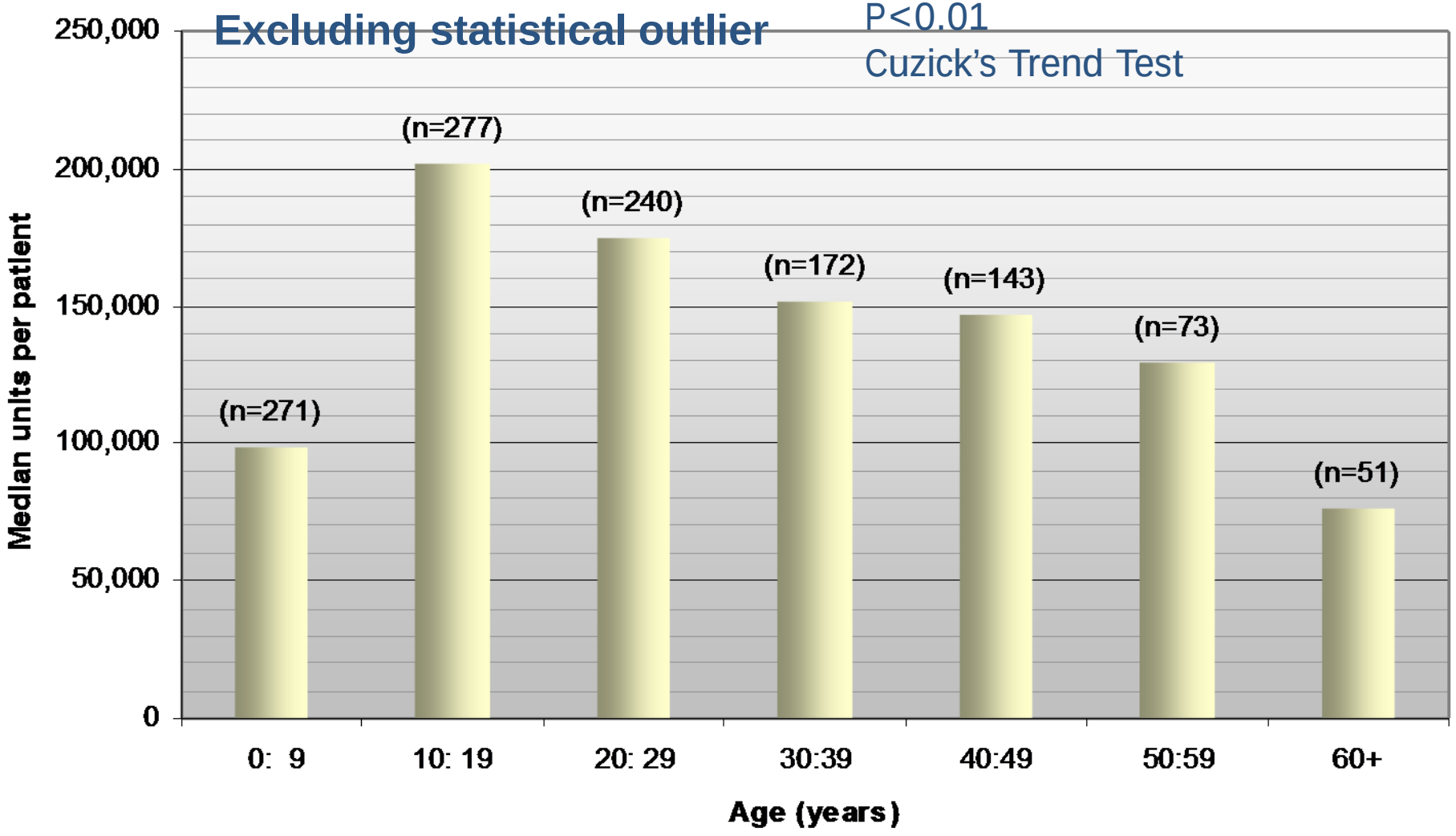


Median annual Factor VIII/IX usage broken down by brand: Non-inhibitor pts using only one product in 2006.

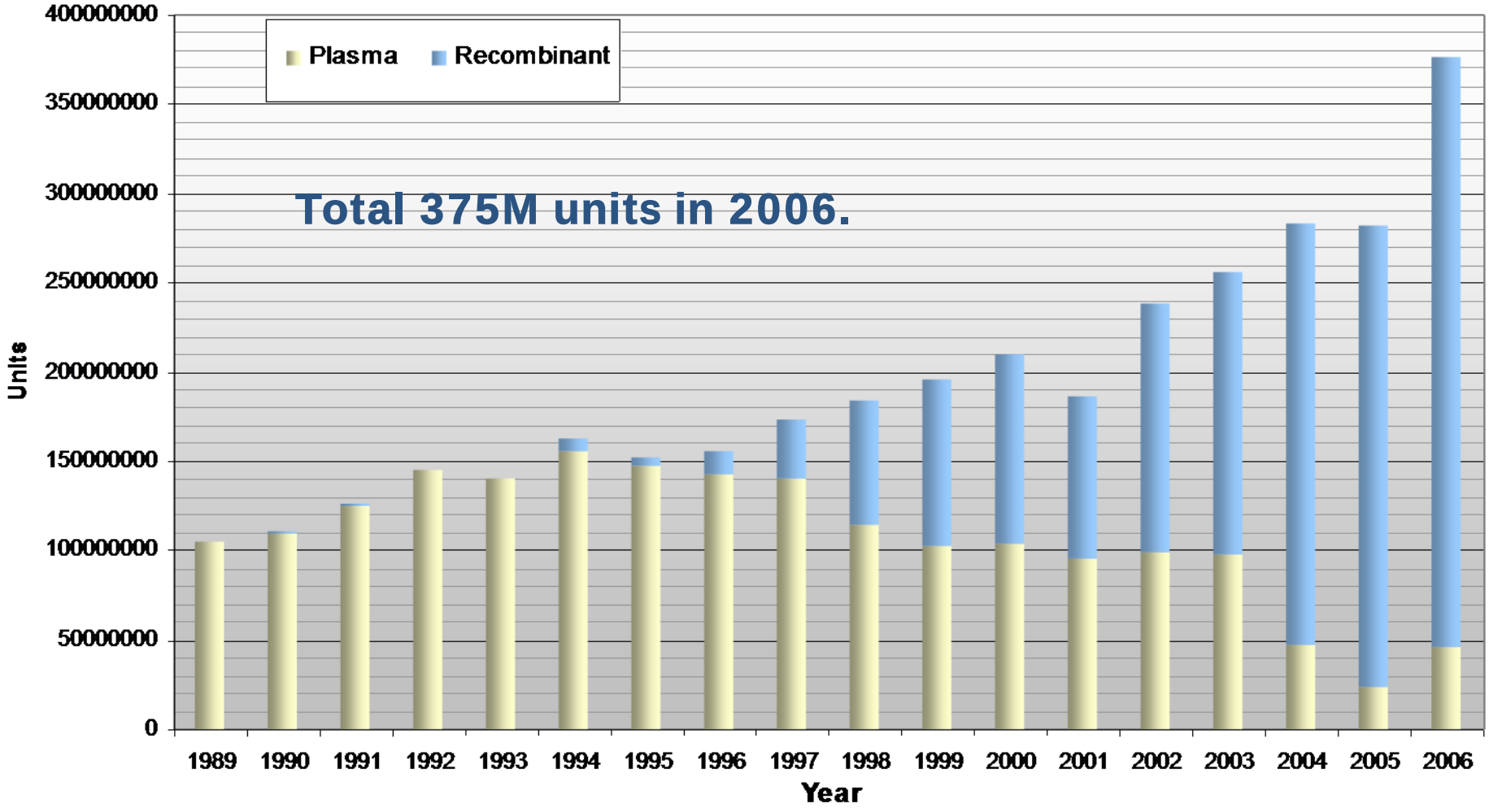


(numbers) of patients. *[non-parametric 95% confidence interval]* .

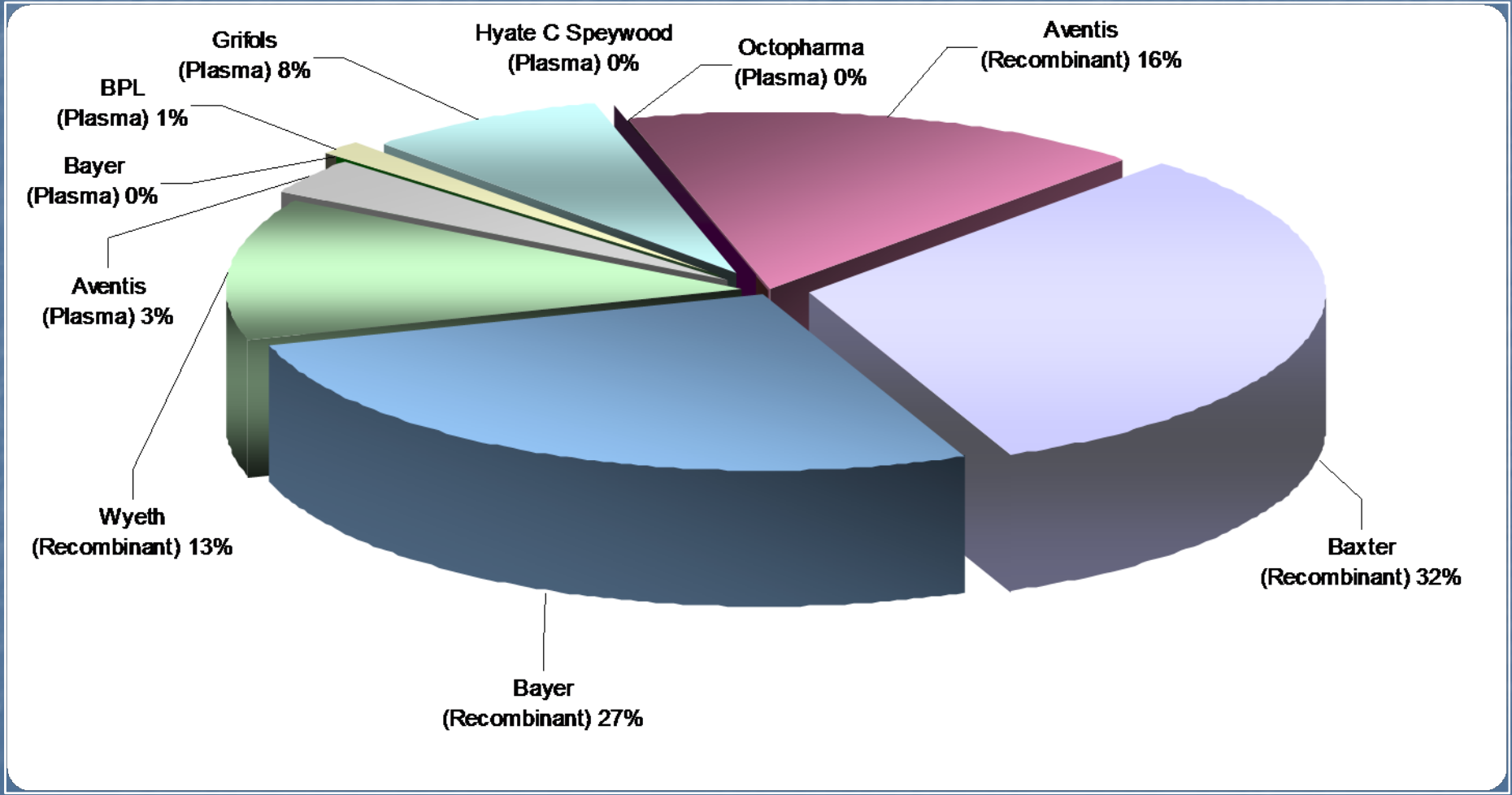
Median factor usage, severe haemophilia A (no inhibitor), by age 2006.



UK Factor VIII usage 1989-2006



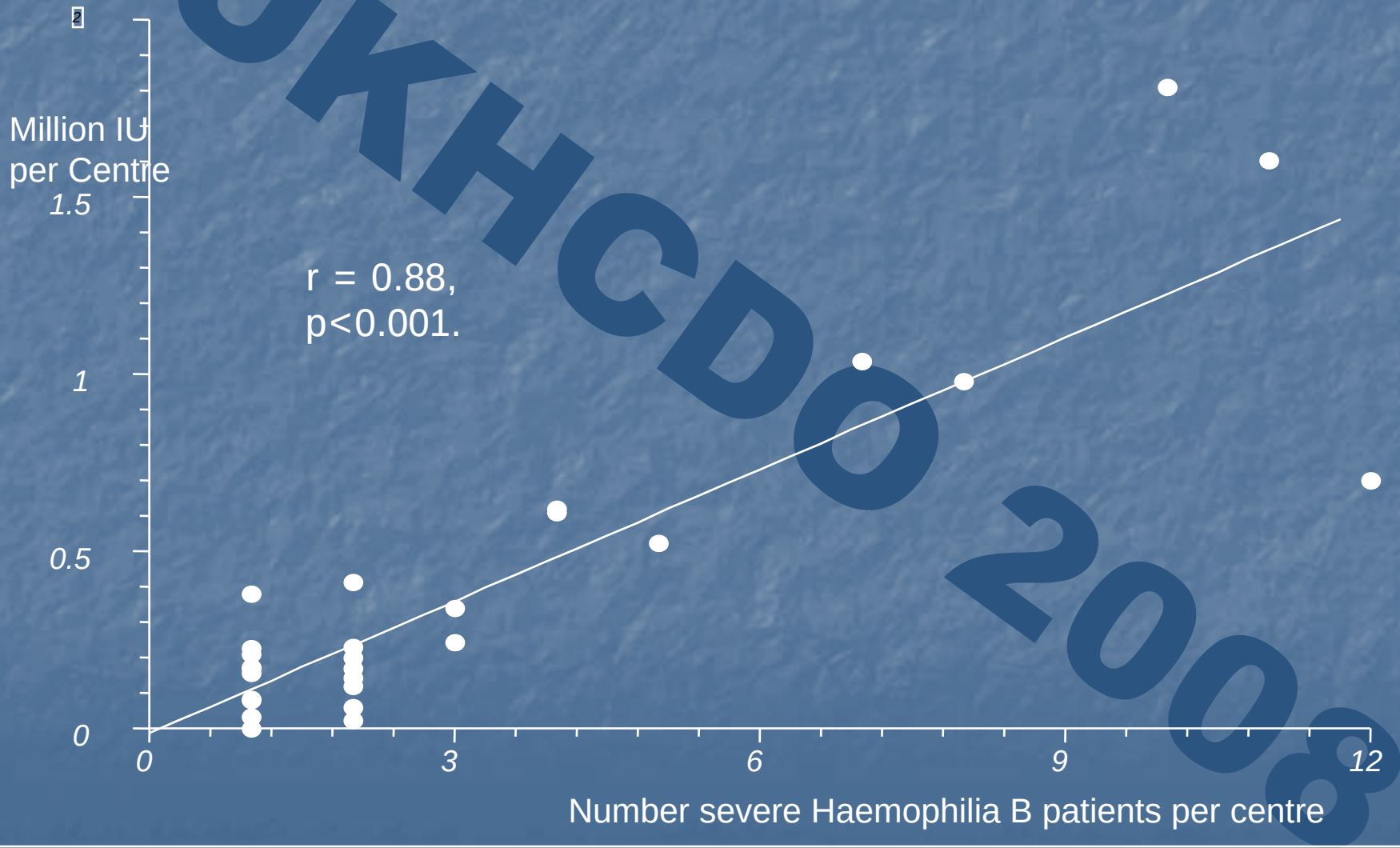
Factor VIII UK Market share 2006.



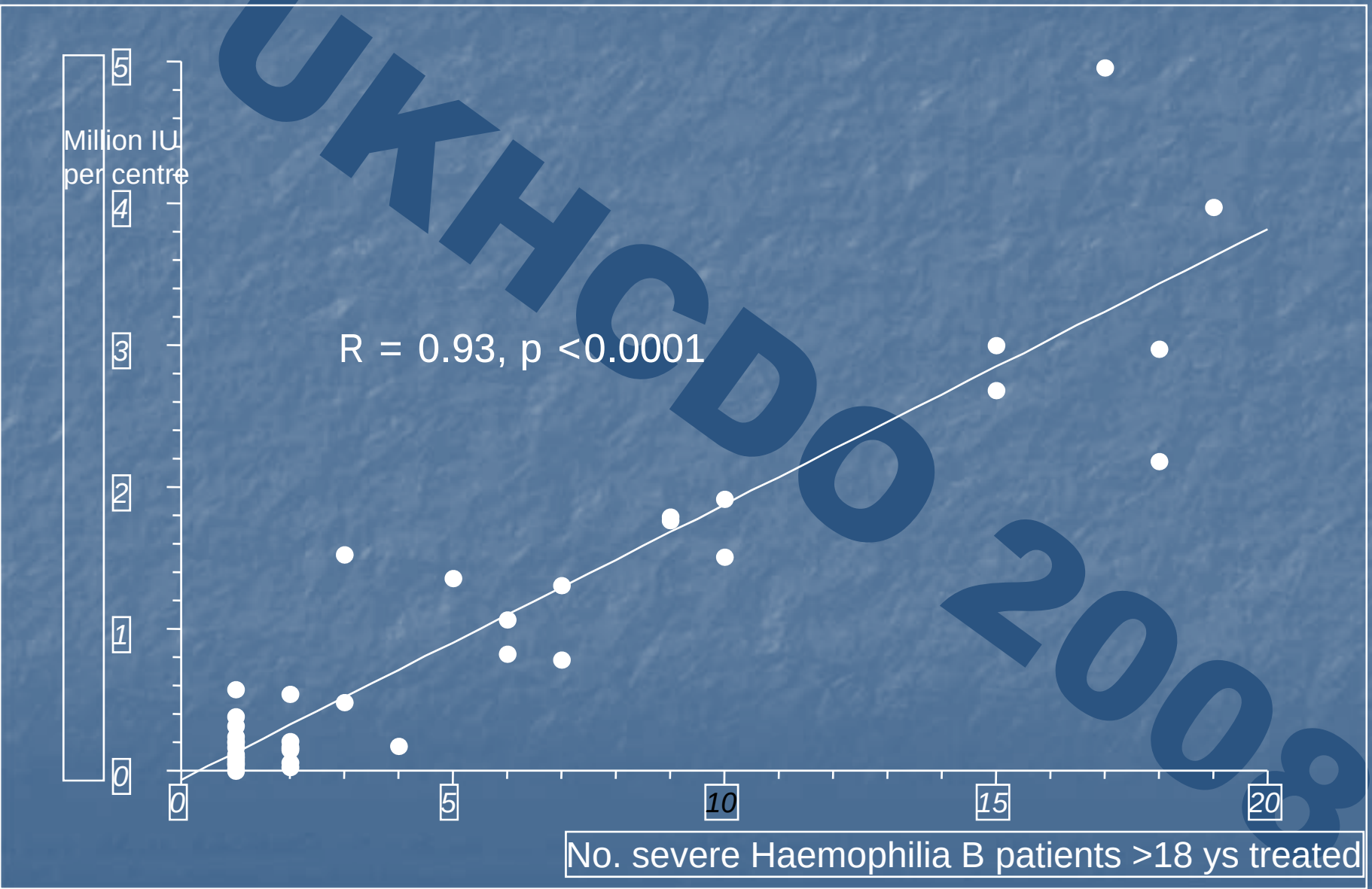
Factor VIII/IX inhibitors by disease severity

Severity (IU/dl)	<1	1-<5	>5
VIII In Register	239	173	17
	10.1%	12.6%	0.81%
Rx in 2006	132	17	13
	8.79%	4.16%	1.28%
IX In Register	7	4	1
	1.565	0.96%	0.28%
Rx in 2006	7	0	1
	2.27%	0	0.59%

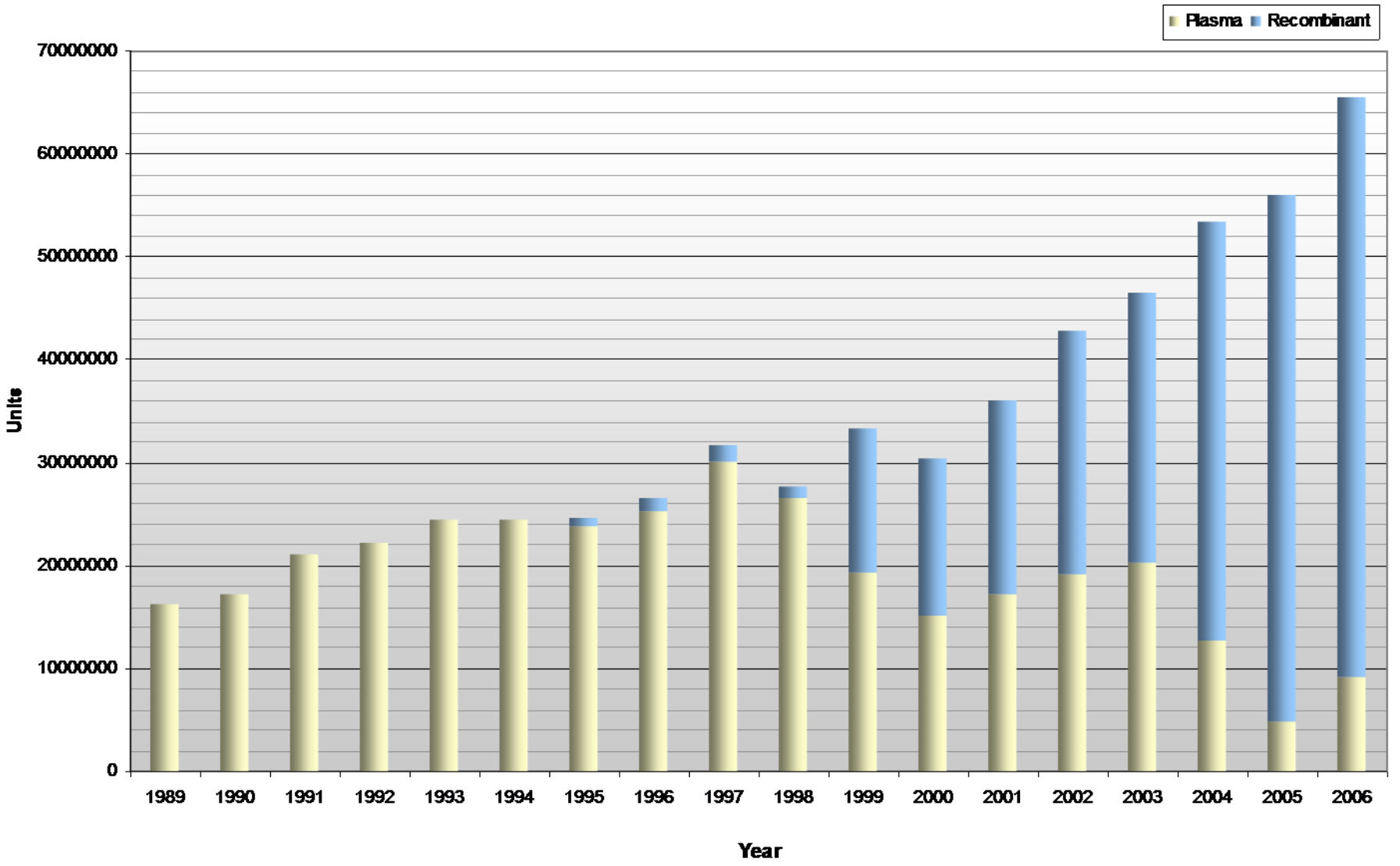
Units of factor IX used per centre relative to the number of patients <18 yrs treated



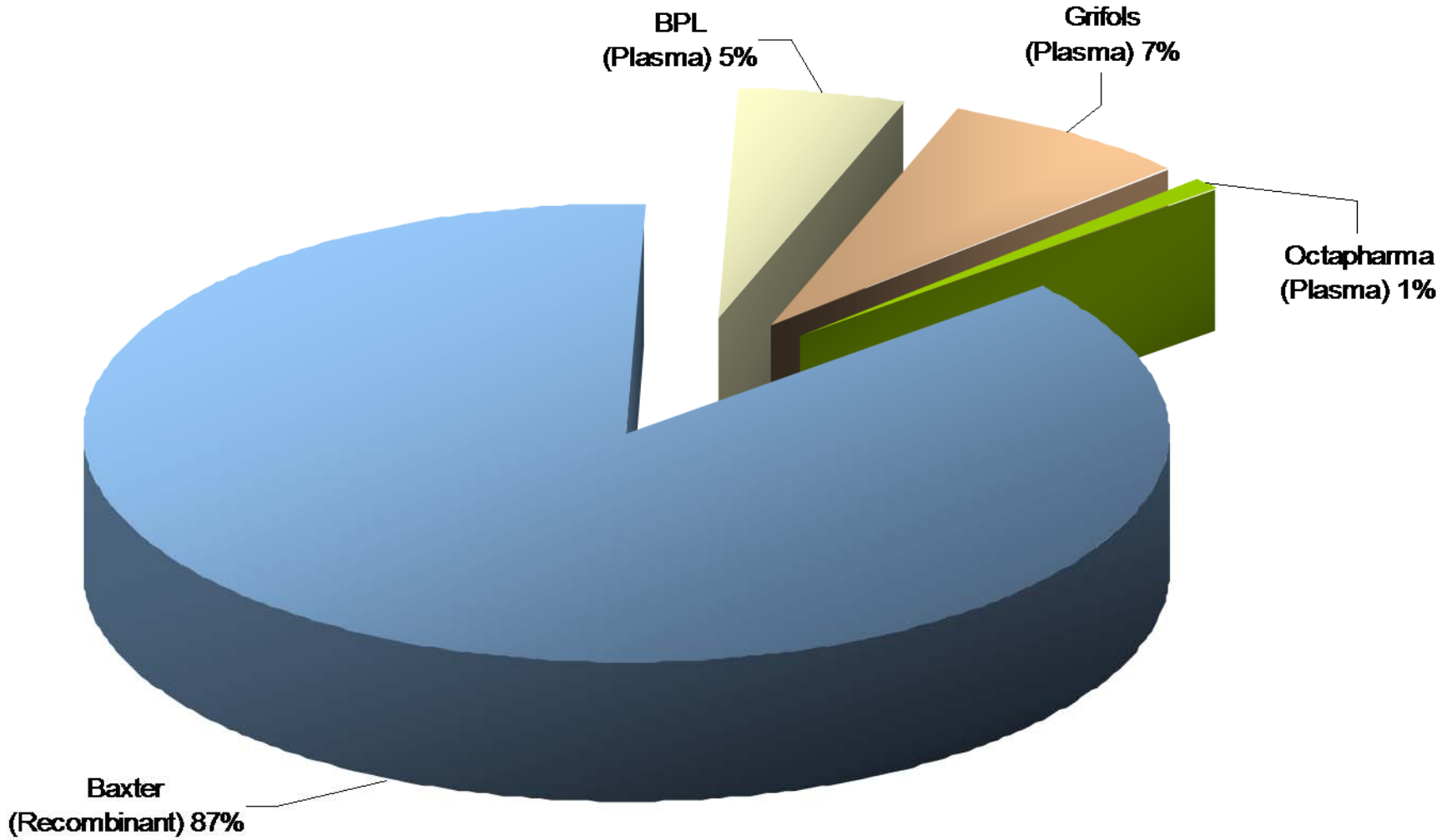
Million Units fIX per centre relative to number of haemophilia B Pts > 18yrs treated.



UK Factor IX usage 1989-2006



UK Factor IX market share 2006.



Estimate of prevalence of hepatitis C in UK Bleeders up to 2006.

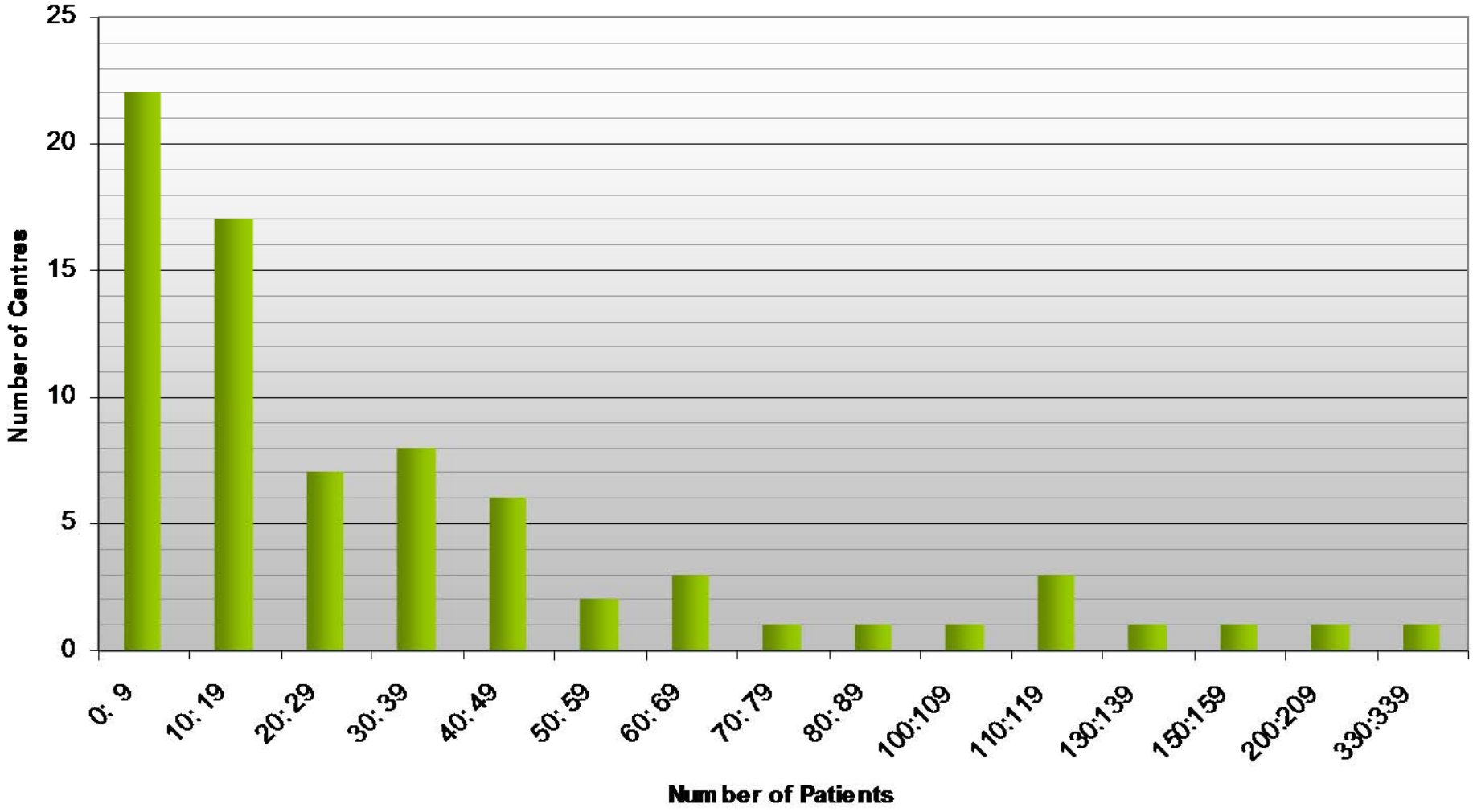
Diagnosis	total	died	Alive
Haemophilia A	3450	1502	1948
Haemophilia B	713	173	540
V W Disease	276	62	214
Other Disorders	250	67	181
Total	4689	1804	2883

- *Estimate is based on concentrate treatment before 1986.*
- *15% will have remitted spontaneously.*
- *An unknown number will be already successfully treated.*
- *Deaths quoted are from **all causes** over a 20 year period.*
- *Death rate from hep C: - 5-8 per year in recent years.*

Principal causes of Death: Haemophilia A & B and VW Dis. 2006

Carcinoma	16
Infection (non HIV)	16
Ischaemic Heart Disease	10
Cerebral Haemorrhage	5
Miscellaneous haemorrhage	7
Liver failure	3
Hepatocellular carcinoma	2
HIV	1
Unknown	9
Total	78

Figure 14 - Total number of severely affected patients with Haemophilia A, Haemophilia B or von Willebrand's Disease treated by UK Haemophilia Centres



Acknowledgement

We would like to thank the centre directors and the Haemophilia Nurses and Data Managers for all their help during the year and for providing us with their data in a timely manner. This is the most complete return that we have ever had, covering 96% of registered patients. This would not have been possible without their hard work and good humour.

The production of this report is very much a team effort, and so I would like to extend my special thanks to the NHD team, and particularly, Rob Hollingsworth, Lynne Dewhurst, Jessica Smith, Amir Rowaichi and Enis Muminovic.