

Canadian Hemophilia Registry – Annual Report 2007

1. A summary of changes since May 2006 is as follows:

	2006	2007	Abs.Incr	% incr.
VIII	2349	2435	86	3.7
IX	572	595	23	4.0
VWD	2564	2818	254	9.9
RareCoag	544	625	81	14.9
RarePit	326	372	46	14.1
C1EI	14	25	11	78.6
HIV+	229	226	-3	-1.3
TOTAL	6598	7096	498	7.5

2. The number of individual registrants has increased by 7.5% since May 2006, the greatest proportional increases being in Rare Platelet Disorders (14.1%) and Rare Coagulation Disorders (14.9%). The largest absolute increase was in the VWD population (254 cases).
3. There continue to be deaths of patients from liver failure, statistics to be presented.
4. Concerns.
- CHR entries “not known” to clinics – as per 2006. Recommendation: Hospital ID numbers be recorded in CHARMS registration (Patient Details) screen.
 - The amount of data entered should be reviewed. Recommendations to be made at AGM.

Submitted by Irwin Walker, April 27, 2007.

Appendix A - Historical Data, 2003-2006

2006 data as at April 16, 2006; other years as per CHR website

YEAR		2003	2004	2005	2006
TOTALS		4777	5515	5947	6362
Factor VIII	total	2162	2221	2291	2348
	adult	1526	1551	1617	1680
	pediatric	635	670	674	668
	severe (incl.inhib).	626	653	666	677
	inhibitor total	83	80	80	79
	inhib. Mild/mod	11(13%)	12(15%)	12(15%)	13(16%)
	female total	95	112	123	135
Factor IX	total	547	551	565	572
	adult	383	394	414	424
	pediatric	164	157	151	148
	severe (incl.inhib).	138	139	141	139
	inhibitor total	4	4	4	3
	inhib. Mild/mod	1	1	1	0
	female total	49	48	50	54
VWD	total	2068	2156	2366	2553
	adult	1422	1516	1691	1868
	pediatric	646	640	675	685
	female	1069	1142	1274	1417
	male	714	734	813	865
	unknown sex	285	280	279	271
Rare Coagulation	total		373	471	549
Rare Platelet	total		214	254	326
C1 Esterase Def.	total				14

Appendix B – Age Profiles, Hemophilia cf. Canadian Population (Statistics Canada).

