

## **Canadian Hemophilia Registry – Annual Report 2006**

1. A summary, and comparison with previous years, appears as Appendix A.
2. The number of individual registrants has increased by 6.7% since May 2005, the greatest proportional increases being in Rare Platelet Disorders (28%) and Rare Coagulation Disorders (17%). The largest absolute increase was in the VWD population (187 cases).
  - a. There have been two requests for specialized data, not directly available from [www.ahcdc.ca](http://www.ahcdc.ca), requiring specific consent and/or extra data from centres, from the Prophylaxis Subcommittee and VWD Subcommittees.
3. The profiles of the severe hemophilia A & B populations differ from that of the Canadian population, while the profiles of mild hemophilia A & B closely approximate the Canadian profile (Appendix B)
4. Publication: Arnold D et. al. Mortality Rates and Causes of Death among all HIV-Positive Individuals with Hemophilia in Canada over Twenty-one years of Follow Up. Blood 2006 – Prepublished as First Edition Paper, March 21<sup>st</sup>, 2006.
5. Concerns.  
CHR entries “not known” to clinics – to be addressed at the AGM.

Submitted by Irwin Walker, April 16, 2006.

Attachments: Appendices A and B.

**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).

