



Canadian Hemophilia Registry – Annual Report 2009

Incorporating the Rare Inherited Bleeding Disorders Registry

1. A detailed report of the Rare Inherited Bleeding Disorders Registry will be presented separately.
2. Statistics on the CHR website will be updated to April 2009.
3. A summary of changes (as at March 21, 2009) since May 2008 is as follows:

	2006	2007	2008	2009	2008>9 Abs.Incr	2008>9 % incr
VIII	2349	2435	2519	2544	25	1.0
IX	572	595	607	615	8	1.3
VWD	2564	2818	3066	3240	174	5.7
RareCoag	544	625	714	739	25	3.5
RarePlt	326	372	500	558	58	11.6
C1EsteraseInhib.	14	25	30	45	15	50.0
Hypogamma.			40	64	24	60
TOTAL	6369	6870	7476	7805	329	4.4
HIV+ (originally 652)	229	226	222	212	-10	-4.5

4. Projects

Prevalence of inhibitors during 2007-8. Poster at WFH 2008.

5. Recommendations

- a. The need for continued reporting is emphasized. There is no direct connection between CHR and clinic CHARMS programs i.e. updating CHARMS does not update CHR.
- b. Reporting of deaths is important, including Year and Cause of death.
- c. Ensure ongoing identity of patients e.g. by recording hospital ID# in Patient Detail screen in CHARMS.
- d. When reporting, refer to up-to-date forms on website (www.ahcdc.ca) for data to be reported eg HCV and VWF lab data no longer required.
- e. Note variable definitions of status Active. Many patients, particularly those with mild disorders are often seen at long intervals, or not at all. How are they to be recorded in CHR? Suggestion (for discussion if possible): Contact all patients at one to two yearly intervals – if present in region and alive, retain on CHR as Active, otherwise record Lost to Follow Up or Deceased.

Submitted by Irwin Walker, March 21, 2009.