

AHCDC **REGISTRY SUB-COMMITTEE REPORT** MAY 2003

1. INFRASTRUCTURE:

- a. The CHR software, operating almost unchanged since 1988 has been reprogrammed, by Cecilia Stiles of MDT software. This will allow:
 - i. Accommodation of all bleeding disorders, beyond just hemophilia A and B, i.e. VWD (completed) and RIBDR (in process).
 - ii. Documentation of incidence (over time) as well as prevalence (snap-shot) of inhibitors.
 - iii. Greater flexibility to disseminate data e.g. by email and website.
 - iv. Easier export of data to statistical programs for data analysis,
 - v. Greater security (see b.).
- b. The database has been moved to McMaster University Medical Centre, on a central server.

2. 2003 UPDATE:

- a. All clinics have responded to the request for updates.
 - i. Some clinics find it difficult to respond quickly.
 - ii. Clinic staffing varies considerably.
 - iii. A few clinics are following previous recommendations in informing CHR of changes in real time.
 - iv. Clinics that maintain updated clinic lists in CHARMS report that requests for updates pose no administrative burden.
 - v. Some clinics are more aware than others regarding status of individuals in their area.
- b. Updating the VWD registry has made this update considerably more burdensome than previous, both for clinics and CHR.
- c. Baseline severities of patients with inhibitors are being documented.
- d. To effectively track the incidence (c.f. prevalence) of inhibitors, exact dates of B.U. assays that document changes in status will need to be recorded.

3. RESEARCH:

- a. Poster presentation at WFH 2002:
 - i. "Decreasing Death Rate from HIV Infection".

4. PAST PUBLICATIONS: (attached, page 2).

5. FUTURE PLANS:

- a. Publications:
 - i. Update on Deaths in HIV- and HCV-infected individuals.
 - ii. Potential publications on "inhibitors", and "VWD".
- b. Formation of Website (accessible through AHCDC website).
- c. Incorporation of Unique Identifier (UI) numbers.
- d. Request actual dates of inhibitor assays on patients with changing inhibitor status.
- e. Incorporation of Rare Inherited Bleeding Disorders registry.
- f. VWD Subcommittee to provide guidelines regarding collection of VW data.
- g. Recommend to clinic directors to review clinic data regarding i) Patients VW classification and ii) possible inactive patients i.e. those moved, lost or deceased.

CHR PUBLICATIONS

Peer Reviewed

1. Walker I. Survey of the Canadian Hemophilia Population. *Can J Public Health* 82:127-129, March/April 1991.
2. Canadian Hemophilia Clinic Directors Group. Effect of using safer blood products on prevalence of HIV infection in haemophilic Canadians. *Brit Med J* 306: 306-7, 1993.
3. Blanchette V, Walker I, Gill P, Adams M, Roberts R, Inwood M, Canadian Hemophilia Clinic Directors Group. Hepatitis C Infection in Patients with Hemophilia. Results of a National Survey. *Transfusion Medicine Reviews*. 1994;8:210-217.
4. Walker I et al. The Canadian Hemophilia Registry as the Basis for a National System for Monitoring the Use of Factor Concentrates. *Transfusion* 1995; 35:548-551
5. Walker I, Julian J. Association of Hemophilia Clinic Directors of Canada. Causes of Death in Canadians with Hemophilia 1980-95. *Hemophilia* 1998; 4:704 713

Associated Editorial to reference 4

Van Aken WG. The need for a national blood product monitoring system: role of hemophilia registries. *Transfusion* 1995; 35:540-541.

Meeting Abstracts

1. Walker I, Canadian Hemophilia Clinic Directors Group. Enumeration of the Canadian Hemophilia Population. XIX International Congress of The World Federation of Hemophilia 1990, Washington, DC. Book of Abstracts p.45, 1990.
2. Walker IR, Canadian Hemophilia Clinic Directors Group. HIV in Canadians with Hemophilia: Prevalence, Mortality and the Impact of Safer Factor Concentrates. XX Congress of the World Federation of Hemophilia, Athens, Greece, October 1992
3. Blanchette VS, Walker I, Inwood M, Adams M, Gill P and the Canadian Hemophilia Clinic Directors Group. Prevalence of Hepatitis C infection in individuals with Hemophilia: Results of a National Study. XX Congress of the World Federation of Hemophilia, Athens, Greece, October 1992.
4. Walker IR, and the Canadian Hemophilia Clinical Directors Group. Canadian Hemophilia Registry (CHR) - Update and Assessment of Completeness. XXI International Congress of the World Federation of Hemophilia, Mexico City, Mexico. April 1994.
5. Walker I, Association of Hemophilia Clinic Directors of Canada. Causes of Death in Canadians with Hemophilia 1980-93. National Hemophilia Foundation Conference. Liver Disease in Hemophilia: New Directions in Diagnosis, Management and Treatment. Atlanta, Georgia, March 3-5, 1995.
6. Walker I, Julian J. Causes of Death in Canadians with Hemophilia. XXII International Congress of the World Federation of Hemophilia, Dublin, Ireland 1996.
7. Walker I, Julian J, AHCDC, CANHC.. Canadian Hemophilia Registry - HIV, HCV and mortality. XXIV Int. Congress of the World Federation of Hemophilia, Montreal, Canada, July 2000.
8. Laurenson L, et al. Comparison of Australian and Canadian National Haemophilia Registry Data. International Society on Haemostasis and Thrombosis, Paris, France, June 2001.
9. Walker I, Julian J, AHCDC, CANHC. Decreasing Death Rate from HIV Infection, World Federation of Hemophilia, Seville, Spain, May 2002.