

Canadian Hemophilia Registry

Annual Report to AHCDC, April 2004

Activities:

1. An national update was carried out during 2003.
2. The VWD registry was transferred from Kingston.
3. The Rare Inherited Bleeding Disorders Registry is well advanced and will be available during the next few weeks, CHR numbers having been assigned to patients with coagulation disorders, platelet disorders pending. RIBDR will be incorporated on the web.
4. CHR is now available on the web, through the AHCDC home page. Reports are available for hemophilia A and B, and von Willebrand Deficiency.
5. Inhibitor patients are now being classified according to underlying severity of hemophilia (Mild/Moderate/Severe).

Recommendations:

1. From Inhibitor Subcommittee: That actual dates and results of inhibitor assays be recorded. The CHR program has been modified to accommodate this data. A letter to the clinics is being prepared.
2. Recommend to clinics to review clinic data regarding i) Patients' VW classification and ii) Patients not recently seen e.g. last two years, to reclassify to moved, lost to follow up, or deceased.

Research:

1. A paper is being prepared by Dr. Donnie Arnold (CBS Fellow) documenting the survival of the HIV positive patients.
2. CHR is assisting the VWD Quality of Life project.

End.

Sunday, March 14, 2004