

**Association of Hemophilia Clinic Directors of Canadian
Canadian Hemophilia Registry
Report to Annual General Meeting
Toronto, Ontario
May 26, 2001**

The Canadian Hemophilia Registry has continued to issue statistics to a variety of individuals, on request; requests have come predominantly from individual AHCDC members and pharmaceutical companies.

Publications

Poster at World Federation of Hemophilia, Montreal, July 2000

Collaboration with Dr. R. Baker from the University of Western Australia - A comparison of the Canadian and Australian registries, to be presented at ISTH, Paris, July 2001.

Updates

An update request was made to clinics March 2001.

Future Developments

The Canadian Hemophilia Registry will be reprogrammed in an Access database. It will be expanded to include the Von Willebrand Disease Registry, and the genetic mutations database. All rare factor deficiencies will be included in the updated version.

Future Projects

Publication of causes of death. This will be prepared once the current update is completed.

Request from Dr. Blanchette to establish rare factor deficiency registry (see above).

An analysis of patients with inhibitors, and their management - Dr. Manuel Carcao