

PROPHYLAXIS SUB-COMMITTEE REPORT: 2006

ASSOCIATION OF HEMOPHILIA CLINIC DIRECTORS OF CANADA

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MS. P. HILLIARD

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The major activity of the Prophylaxis Subcommittee during 2005/2006 has been the Canadian hemophilia dose escalation prophylaxis study (CHPS 1) and the extension study CHPS 2. Co-Principal Investigators for the study are Dr. Victor Blanchette and Dr. Brian Feldman.

CHPS 1

The first patient entered the study in July 1997. At completion of the initial study 25 boys were enrolled from 10 hemophilia treatment centres. Patients were followed for a total of 1150 patient months (mean 46 months /pt). The results of the study will be published in Journal of Thrombosis and Hemostasis in June 2006.

CHPS 2

It was decided by the investigators to continue to follow boys enrolled on CHPS 1 and to keep patient enrollment open. We have funding from Bayer for 3 years. There are currently a total of 46 boys enrolled (CHPS 1 and CHPS 2) in 11 centres. The boys have been followed an average of 61 months (Range: 7-106 months).

CHPS 3

In order to continue following the boys enrolled on CHPS 1 and CHPS 2 the investigators have submitted to the CIHR/Industry Partnership competition for a further 5 years of funding. The industry partner is Bayer and the application was submitted in April, 2006.

In CHPS 3 we will continue to record bleeding frequency; serial physiotherapy and imaging assessments will be performed.

Study aims are as follows:

- to determine factors that determine the bleeding frequency of bleeding in boys with severe hemophilia A i.e. what factors determine which boys require more frequent infusions to maintain an acceptable level of bleeding.
- to compare the costs and benefits of Canadian tailored prophylaxis with intermediate dose prophylaxis (i.e. as practiced in the Netherlands), aggressive on-demand therapy and full-dose prophylaxis (i.e. the Malmö prophylaxis model as practiced in the USA (Denver) randomized trial of prophylaxis).

Clinical Endpoints Survey

The purpose of this survey was to develop consensus definitions of various terms in relation to prophylaxis e.g. type of prophylaxis, definitions of target joint bleeds etc. The results from the first survey were compiled and a second survey was sent out to all members of the AHCDC, CANHC and the Physiotherapy group. The study has been completed. The abstract was accepted as a poster at WFH. The manuscript has been submitted to Haemophilia.

International Prophylaxis Study Group (IPSG)

Members of the Prophylaxis Subcommittee, Dr. Blanchette Dr. Rivard and Pam Hilliard are actively involved in activities of the IPSG. This group continues to work in the area of Prophylaxis.

- On behalf of the IPSG the MRI Expert Working Group has published a single internationally approved MRI scoring scale.
- The PT Expert Working Group has received funding for a validation study of the Hemophilia Joint Health Scale that was developed by the expert working group.
- The Outcome Measures Expert Working Group is working to develop guidelines for the Quality of Life and Economic tools for use in prophylaxis clinical trials

Future Studies

- A study of prophylaxis in adolescents/young adults is planned with support from the Baxter research fund

Victor S. Blanchette
Chairman
Prophylaxis Sub Committee

Publications

Abstracts: World Federation of Hemophilia 2006

Definitions for Hemophilia Prophylaxis and its Outcomes: The Canadian Consensus Study

S. Ota, M. McLimont, M. Carcao, Elizabeth Paradis, Nicole Graham, B.M. Feldman

Publications:

Definitions for haemophilia outcomes. S. Ota, M. McLimont, M. Carcao, Elizabeth Paradis, Nicole Graham, B.M. Feldman

Submitted to Haemophilia, March 2006

Tailored prophylaxis in severe hemophilia A: Interim results from the first 5 years of the Canadian Hemophilia Primary Prophylaxis Study (CHPS)

Brian M. Feldman, Mohan Pai, Georges E. Rivard, Sara Israels, Man-Chiu Poon, Christine Demers, Sue Robinson, Hung Luke, John K. M. Wu, Kulwant Gill, David Lillicrap, Paul Babyn, Marjorie McLimont, Victor S. Blanchette

Accepted for Publications: Journal of Thrombosis and Haemostasis