

**AHDCDC Prophylaxis Sub-Committee
Report 1998-99**

Committee Members:

- [Dr. Victor Blanchette](#) (Chairperson)
 - [Dr. Georges Rivard](#)
 - [Dr. Susan Robinson](#)
 - [Dr. Sara Israels](#)

Sub-committee Activities:

The major activity of the Prophylaxis Subcommittee during 1997/1998 has been the Canadian Hemophilia Dose Escalation Prophylaxis Study. This study is funded by the Canadian Blood System and Bayer. Co-Principal Investigators for the study are Dr. Victor Blanchette and Dr. Brian Feldman. Other Co-Investigators and Steering Committee members are listed in [Appendix A](#).

The first patient was entered on study in late June 1997; currently 18 cases are entered from nine hemophilia treatment centres and 6 potential cases await recruitment. Five cases were ineligible for study (4 cases-positive inhibitor at entry, 1 case-intracranial hemorrhage requiring intensive factor replacement therapy and subsequent prophylaxis). Patients have been followed on study for a total of 234 patient months. ([Appendix B](#))

There have been a total of 108 hemorrhagic episodes requiring therapy in the 18 study cases - 94 soft tissue hemorrhages and 14 hemarthroses. Two patients have been escalated to twice weekly infusions. Nine of the 18 patients have port-a-catheters. Eleven of the patients are receiving infusions in a hospital clinic/ward setting, seven in the home setting. Nine of the patients on study required baseline X-rays of one or more joints based on a history of hemarthrosis before entry into the study; data is presented in [Appendix C](#).

Physical therapy scores for individual joints are obtained using a modified World Federation of Hemophilia (WFH) scoring system. A subset of patients have total scores in the 0-2 range i.e. minimal abnormality if one assumes that a perfect physical therapy score is 0/0. The clinical significance of these observations in children ages 1-2.5 years requires further evaluation. Consideration will be given to the prospective definition of normal scores for the modified WFH scale using healthy non-hemophilic children.

Issues for discussion at the 1999 meeting will include:

- Impact of the recent "CJD" concern on the Canadian Prophylaxis Study.
- Protocol violations and, in particular, variations in factor dosage.
- A prospective evaluation of the Canadian dose escalation protocol in boys with severe hemophilia (factor VIII:C <2%) ages 2.5 - 10 years: a potential new Canadian or Canadian/U.S.A. Study.
- Potential for a Canadian dose escalation study in young boys with severe hemophilia B (factor IX level < 2%) ages 1 - 2.5 years.

Victor S. Blanchette Chairman Prophylaxis Sub-Committee

Canadian Hemophilia Prophylaxis Study

Appendix A

Core Study Committee

- Dr. Victor Blanchette, Primary Co-Investigator
- Dr. Brian Feldman Primary Co-Investigator
- Susan Henriques, Study Co-ordinator
- Ann Marie Stain, Regional Nurse Coordinator
- Pam Hilliard, Toronto Regional Physiotherapy
- Dr. Paul Babyn, Study Radiologist
- Dr. Doug Hedden, Orthopaedic Surgery
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Additional Oversight Committee

- Dr. Jerry Teitel, Haematology, St. Mike's Hospital, Toronto
- Dr. Marilyn Manco-Johnson Haematology, Mountain States Regional Hemophilia Program, Denver
- Dr. Louis Aledort Haematologist New York
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Regional Steering Committee

- Dr. Sara Israels, Manitoba Cancer Treatment & Research Foundation
- Dr. Georges Rivard, Division of Pediatric Hematology, Directeur, Clinique d'hématologie Hôpital Ste-Justine
- Dr. Sue Robinson Director, Hemophilia Clinic Q.E.II Health Sciences Centre

Local Site Investigators

- Dr. Dorothy Barnard, Division of Hematology/Oncology, IWK-Grace Health Centre
- Dr. Christine Demers, Directeur, Centre de l'hémophilie, Hôpital du Saint-Sacrement
- Dr. Mason Bond, Director, Hemophilia Centre, Montreal Children's Hospital
- Dr. Brian Koon-Hung Luke, Director, Hematology/Oncology, Children's Hospital of Eastern Ontario
- Dr. Sean Dolan Director, Hemophilia Program, Saint John Regional Hospital
- Dr. Mohan Pai Director, Hamilton/Niagara Regional Hemophilia Centre, Hamilton Health Sciences Corporation
- Dr. Kulwant Gill, Hematology Department, Laurentian Hospital
- Dr. Man-Chiu Poon Director, Hemophilia Program, Foothills Hospital
- Dr. Jordan Herst, Director, Hemophilia Program, Thunder Bay Regional Hospital
- Dr. Sheldon Rubin Director, Hemophilia Program, The Moncton Hospital
- Dr. Laurence Jardine, Division of Pediatric Hematology, Janeway Child Health Centre
- Dr. John Wu, Division of Hematology/Oncology, B.C. Children's Hospital

Local Site Nurse-Coordinators

- Pat Klein , Alberta Children's Hospital
- Lois Lindner, Mary Pack Arthritis Centre
- Nora Schwetz, Health Sciences Centre

- Carol Mayes, Saint John Regional Hospital
- Dorine Belliveau, The Moncton Hospital
- Heather Richards, Janeway Child Health Centre
- Sue Ann Hawes, IWK/Grace Health Centre
- Ann Marie Stain, Hospital for Sick Children
- Elizabeth Paradis, Laurentian Hospital
- Diane Bissonette, Children's Hospital of Eastern Ontario
- Julia Sek, Hamilton Health Sciences Centre
- Carol Edwards, Thunder Bay Regional Hospital
- Claudine Amesse, Hôpital Ste-Justine
- Ginette Lupien, Hôpital du Saint-Sacrement
- Sylvie Lacroix, Montreal Children's Hospital

Local Site Physiotherapists

- Jennifer Aikenhead, Alberta Children's hospital
 - Linda Mickalishen, Royal University Hospital
 - Jane Neil, B.C. Children's Hospital
 - Judy Fox, Ottawa General Hospital
 - Kathy Mulder, Child Health Sciences Centre
 - Heather Zuker, Hamilton Health Sciences Corp
 - Patti Steele, Saint John Regional Hospital
 - Donna Langen, St. Joseph's Care Group
 - Denise Pellerin, Moncton Hospital
 - Nick Zourikian, Hôpital Ste. Justine
 - Colleen Jones, Janeway Child Health Center
 - Gaetan Thibault, Hôpital Ste-Sacrement
 - Bethany Lezama, IWK-Grace Health Center
 - Lorraine Fischer, Montreal Children's Hospital
 - Pam Hilliard, Hospital for Sick Children
 - Sally Spence, Laurentian Hospital
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Canadian Hemophilia Prophylaxis Study

Appendix B

Patient Follow-up Summary

Patient	Port-a-Cath	Length of Follow-Up (Mths)	# Surface Bleeds	# Joint Bleeds	# Escalated to 2x/week tx.
201	X	11	10	2	X
301	X	5	5	0	
401		15	11	0	
402		4	1	1	
801	X	17	4	2	
901		15	2	0	
902		18	4	1	
903	X	17	4	3	X
904	X	6	1	0	
1301		20	5	1	
1302	X	13	5	0	
1303	X	10	2	0	
1304	X	10	11	0	
1305		6	1	0	
1401	X	14	1	1	
1501		17	6 11 Epistaxis	1	
1502		15	5 4 Epistaxis	1	
1601	21	1	1		
TOTALS	9	234	94	14	2
MEAN		13.00	5.40	0.77	

Canadian Hemophilia Prophylaxis Study

Appendix C

Baseline Radiograph Summary Information

(X-rays required at Baseline of joints which bled prior to study enrollment)

Patient ID	X-Ray Location	Findings
201	L Elbow	Normal
801	L Knee	Normal
903	Both Knees	Normal
1301	R Knee	Normal
1302	L & R Knees	Normal
1303	L Knee	Normal
1305	R Knee	Normal
1501	R Knee	Normal
1601	Both Ankles & Knees	Normal
9 (50%)		