

***Association of Hemophilia Clinic Directors of Canada  
Prophylaxis Subcommittee***

**Report to Annual General Meeting  
Montreal, Quebec**

**July 15, 2000**

**Members:**

- Dr. V. Blanchette (Chair)
- Dr. Georges Rivard
- Dr. Susan Robinson
- Dr. Sara Israels

**Activities:**

The major activity of the Prophylaxis Subcommittee during 1999/2000 has been the Canadian Hemophilia dose escalation prophylaxis study. This study is funded by the Canadian Blood Services, Bayer and MRC. 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 July, 1997 ([Appendix B](#)); currently 24 boys are entered from 10 hemophilia treatment centres and 2 potential cases await recruitment. There were 10 cases that were ineligible for study (positive inhibitor at entry - 6 cases).

Patients have been followed on study for a total of 494 patient months. The maximum length of enrollment is 33 months while the minimum is 2 months. Ten of the 24 patients have port-a-catheters. Sixteen of the boys receive their infusions at home while 8 of the boys receive them in a hospital or clinic setting. ([Appendix C](#))

Twelve 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; five boys have had x rays of joints since enrollment in the study. All joint scores have been normal.

Joints scores are measured using a modified World Federation of Hemophilia (WFH) scoring system. All patient scores are in the normal range using this modified scale.

Of the boys on study 6 have had their dose escalated. Five have been escalated to Step 2 and one has been escalated to Step 3.

Victor S. Blanchette  
Chairman  
Prophylaxis Sub Committee

**Appendix A**

## **Core Study Committee: Hospital for Sick Children**

- Dr. Victor Blanchette, Chief, Haematology/Oncology
- Dr. Brian Feldman, Rheumatology
- Dr. Paul Babyn, Study Radiologist
- Dr. Doug Hedden, Orthopedic Surgery
- Ann Marie Stain, Hemophilia Program Nurse Co-ordinator
- Pam Hilliard, Hemophilia Program Physiotherapist
- Marjorie McLimont, Study Co-ordinator

## **Data Safety Monitoring Committee**

- Dr. Jerry Teitel
- Dr. Marilyn Manco-Johnson
- Dr. Louis Aledort

## **Regional Steering Committee**

- Dr. Sara Israels, Division of Pediatric Hematology, Manitoba Cancer Treatment & Research Foundation
- Dr. Georges Rivard, 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. François Jobin, Directeur, Centre de l'hémophilie, Hôpital du Saint-Sacrement
- Dr. Mason Bond, Director, Hemophilia Centre, Montreal Children's Hospital
- Dr. Robert Klaassen, Director, Hematology/Oncology, Children's Hospital of Eastern Ontario
- Dr. Sean Dolan, Director, Hemophilia Program, Saint John Regional Hospital Centre
- Dr. Mohan Pai, Director, Hamilton/Niagara Regional Hemophilia, Hamilton Health Sciences Corporation
- Dr. Kulwant Gill, Director, Hemophilia Program, Laurentian Hospital
- Dr. Man-Chiu Poon, Hematology Department, Foothills Hospital
- Dr. Christine Demers, Directeur, Centre de l'hémophilie, Hôpital du Saint-Sacrement
- Dr. Sheldon Rubin, Director, Hemophilia Program, The Moncton Hospital
- Dr. Marie-France Scully, Hemophilia Program, Janeway Child Health Centre
- Dr. John Wu, Division of Hematology/Oncology, B.C. Children's Hospital
- Dr. John Akabutu, Department of Pediatrics, Walter Mackenzie Health Sciences
- Dr. David Lillicrap, Department of Pathology, Queen's University
- Dr. Kaiser Ali, Division of Pediatrics, Saskatoon Cancer Centre

## **Nurse Coordinators**

- Wilma McClure, University of Alberta Hospital
- Pat Klein, Alberta Children's Hospital
- Lois Linder, 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
- Sherry Purcell, Kingston General Hospital
- Elizabeth Paradis, Laurentian Hospital
- Diane Bissonnette, Children's Hospital of Eastern Ontario
- Julia Sek, McMaster Division
- Carol Edwards, Port Arthur Site
- Claudine Amesse, Hopital Ste-Justine, 1er Videotron
- Ginette Lupien, Hopital du Saint-Sacrement
- Sylvie Lacroix, Montreal Children's Hospital

### Physiotherapists

- Betty Hale, University of Alberta Hospital
- Jennifer Aikenhead, Alberta Children's Hospital
- Bruce Clark
- Kathy Mulder, Child Health Sciences Centre
- Patti Steele, Saint John Regional Hospital
- Denise Pellerin
- Colleen Jones, Janeway Children's Health Centre
- Bethany Lezama, IWK- Grace Health Centre
- Pam Hilliard, Hospital for Sick Children
- Elsie Culham, Queen's University
- Sally Spence, Laurentian Hospital
- Brenda Elliot, Ottawa General Hospital
- Heather Zucker, McMaster Campus
- Donna Langen
- Nick Zourikian, Hopital Ste. Justine
- Gaetan Thibault, Hopital Ste. Sacrement
- Lorraine Fischer, Montreal Children's Hospital
- Linda Mickalishen, Royal University Hospital

### Appendix B

Centre	Recruited Patients	Potential Patients	Ineligible Patients
Toronto	4	1	1
Montreal	4	0	2
Hamilton	5	0	1
Halifax	1	0	1
Winnipeg	2	0	2
Thunder Bay	1	0	0
Quebec City	2	0	0
Saint John	0	1	1

Sudbury	0	0	1
Calgary	3	0	0
Edmonton	1	0	0
Ottawa	1	0	0
Vancouver	0	0	1
TOTALS	24	2	10

### Appendix C

ID #	Months on study	# Index joint bleeds	# Muscle bleeds	# Muco-cutaneous bleeds	# Other bleeds	Dosage step on protocol
1601	33	1	-	1	-	1
1301	32	1	-	7	-	1
902	30	1	-	4	3	1
801*	29	3	-	6	-	1
903*	29	3	-	8	-	2
1501	29	1	-	31	-	2
1502	29	1	-	4	7	2
401	27	-	1	17	2	2
901	27	1	-	1	2	1
1401*	27	1	-	1	-	1
1302*	25	4	1	10	2	1
201*	22	2	-	20	3	3
1303*	22	-	-	2	-	1
1304*	22	-	-	14	3	1
904*	20	-	-	1	4	1
301*	19	-	4	6	-	2
1305	18	-	1	3	1	1
402	15	4	-	6	-	1
1505	11	-	1	1	1	1

1602	9	-	-	1	-	1
202	6	-	-	1	-	1
1506	6	-	-	4	-	1
1201*	5	-	-	2	-	1
203	2	-	1	4	-	1

\*Patients with Port a Cath inserted