

## AHCDC Annual General Meeting – May 2003

### **Emergency Care of Hereditary Bleeding Disorders Subcommittee Report**

This committee was formed last year to work with our colleagues in the AHCDC and liaise with the Canadian Hemophilia Society ER Education Committee.

#### **Background Information:**

Persons with hemophilia or other congenital bleeding disorders may present at emergency rooms for a variety of reasons. Those living far from a hospital with a hemophilia clinic or on vacation may use the emergency room of a local hospital for routine treatment of their bleeding disorder or to access product. Alternatively, in the case of a life-threatening bleed, persons with hemophilia are advised to go directly to the emergency room and persons with hemophilia may present to the ER as a result of an accident or other non-hemophilia related emergencies. The quality of care that the patient with hemophilia receives and the outcomes related to the acute event is directly related to the knowledge and preparedness of the emergency department staff. Failure to appreciate or even consider the diagnosis of a congenital bleeding disorder may lead to misdiagnosis and inadequate, delayed, or inappropriate therapy. Thereby potentially contributing to preventable increases in hemophilia associated morbidity and mortality.

Despite careful review, the optimal means of preventing and managing hemophilic musculoskeletal injury remains controversial. However, there is a consensus among treaters that early recognition of a bleed and rapid intervention to prevent further bleeding is effective in preventing long-term morbidity.

The ER advisory committee of the CHS was formed to try to better understand how emergency departments work and work with them to provide better care for our patient population. Members include Dr. Joe Finkler who works as an ER physician at a large Vancouver hospital, Dr. Cathy Chapman who works as a family physician/ER physician at a rural hospital in Ontario, Rose Jacobson, Lucie Lacasse, and Sherry Purcell as nurses from the Canadian Association of Nurses in Hemophilia Care, and Pam Wilton, Cathie Morris and Erma Chapman as Canadian Hemophilia Society representatives. This whole enormous project is coordinated by Clare Cecchini.

So far, the CHS committee has, in association with members of the AHCDC, developed the following projects:

1. Factor First card
2. Posters to be used in the emergency departments to complement the Factor First card
3. We are working to ensure that the hemophilia emergency care website at <http://www.hemophiliaemergencycare.com/alpha/v06/index.html> includes information about Canadian sites and recommendations for therapy from a Canadian perspective.
4. Cathie Morris at the CHS has spearheaded a project to develop “Prepare to Succeed – A Guide to the ER for persons with Bleeding Disorders”
5. Sherry Purcell is working on a Power Point presentation with information sent by Dr. Scully and others to be available to hemophilia nurses and CHS for use as in-services on the topic of ER treatment of hemophilia.

6. Doctors Rubinger, Finkler, Scully and Chapman prepared an insert for the Medical Post and are working on an article for the Canadian Journal of Emergency Medicine. This will be circulated among the members of the AHCDC.

**Activities of the AHCDC subcommittee:**

1. Dr. Mariana Silva planned to contact training programs to encourage a haematology fellow to work with the committee.
2. Dr. Kent Stobart is working on developing proper search engines to record all the appropriate literature relevant to various areas of practice of hereditary bleeding disorders. He will include the search on emergency care of hereditary bleeding disorders.
3. The members are reviewing the CHS recommended website at <http://www.hemophiliaemergencycare.com/alpha/v06/index.html> and will contribute to this.
4. The members will also review the AHCDC website and are prepared to work with members of the writing committee to develop sections on emergency care.
5. A major project under discussion is to prepare a formal survey of AHCDC members, pediatricians, pediatric hematologists and neonatologists across Canada on the topic of the optimal management of labour and delivery for carrier women known to have hemophilia. We would also like to discuss with Dr. Irwin Walker whether or not we should include a CHARMS module so outcomes of labour and delivery can be properly documented.
6. Dr. Scully has met with Dr. Heather Hume of the CBS at the ASH meeting in December 2002. Basically Dr. Hume is interested in working with our subcommittee to ensure that there are appropriate replacement products in blood banks across the country to deal with major emergencies such as a major motor vehicle accident, for example, which could affect patients with severe bleeding disorder. This is a complex topic. A pilot project is being started in the province of Newfoundland and Labrador. The members of the committee will review emergency plans for the province and provide more ideas to Dr. Scully.
7. Committee members also plan to review medical literature and CME events with regards to ensuring that there is good material out there on management of hereditary bleeding disorders designed for various subspecialists. The committee will also consider writing some articles. Again, further advertising of the Factor First card and other initiatives. The articles could be geared towards orthopedic surgeons, emergency care staff, pediatricians and family care staff. Dr. Scully is planning to write one geared towards laboratory technologists. Also, Dr. Scully mentioned that the CHS committee on emergency care developed an excellent poster and binder to prepare patients with hereditary bleeding disorders returning to the ER. Dr. Scully will email Clare Cecchini, the coordinator for these projects, and ask that she send on this information to the members of the subcommittee. Dr. Mariana Silva suggested that we contact haematology fellows to see if they would be interested in these projects. Dr. Silva will follow up on this. Dr. Rubinger suggested that we look for an ER physician and a nurse to join our subcommittee. The plan for now is that members of the committee will talk with individuals in their local centres to see if there is anybody interested.