

AHCDC Annual General Meeting – April 2004

Emergency Care of Hereditary Bleeding Disorders Subcommittee Report

Members:

Dr. Mary-Frances Scully
Dr. Margaret N. Warner
Dr. Mariana Silva
Dr. Pat McCusker
Dr. M. Rubinger

This committee was formed in 2002 to work with our colleagues in the AHCDC and the CAHNC and to 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.

The ER advisory committee of the CHS was formed to try to better understand emergency departments and work with their staff 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 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. Doctors Rubinger, Finkler, Scully and Chapman prepared an insert for the Medical Post in 2002.
5. Cathie Morris with Sherry Purcell have produced CDroms on the ER management of hemophilia and von Willebrand's disease which are available through the CHS.
6. A vWD version of the manual on Emergency Care is being developed with input from Sherry Purcell, Lucie Lacasse and Rose Jacobson.

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. The members are reviewing the CHS recommended website at <http://www.hemophiliaemergencycare.com/alpha/v06/index.html> and will contribute to this.

3. 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.
4. A 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. An informal email survey showed that currently no Canadian centres have specific local guidelines. However, the committee on Women and Bleeding Disorders led by Dr. Christine Demers has developed an excellent binder on Management of Labour and Delivery in Women with Bleeding Disorders. These have been circulated to Women's Health Programs across the country. We will ask Dr. Irwin Walker whether or not we can include a CHARMS module to document the outcome for labour and delivery for women with hereditary bleeding disorders and their newborn babies.
5. 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. 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.
6. An abstract entitled "Emergency Treatment of Hemophilia". Mary-Frances Scully MD, Margaret N Warner MD, Erma Chapman and Morel Rubinger MD was published in the 2003 ASH Abstract Book but not accepted for presentation.
7. An email survey of AHCDC and CAHNC re the Factor First Card was incomplete. However, all responses received were positive. A number of centres who had devised their own local form of documentation chose to stick with that.
8. Dr. Molly Warner, Dr. Mariana Silva and Dr. Mary-Frances Scully met briefly at another meeting in the fall and developed a "To Do" list.
9. Dr. Scully has developed a presentation on "Emergency Room Issues for Patients Hereditary Bleeding Disorders" for the Wyeth sponsored website called CME on Hemophilia at www.CMEonHemophilia.com.

To Do List

1. Review with Dr. Silva to see if there is a fellow interested to work with this subcommittee.
2. Review with committee members to find a nurse coordinator and ER physician to work with this subcommittee.
3. Review the exact number of hemophilia centres – adult and pediatric – in Canada ?24
4. Review the exact number of emergency rooms
5. Review the number of patients who received replacement products in Quebec and the rest of Canada who are registered with CHARMS and whether or not there are likely to be patients who are not registered or for whom we do not capture data.
6. We are interested in the number of ER visits for patients with hereditary bleeding disorders.

7. We are also interested in knowing the number of units of factor concentrates which are actually administered in ER departments and most importantly, whether or not the patients have received the right products and the number of units given in hospital if the ER data is not available.
8. We would also like to try to document the use of DDAVP and tranexamic acid.
9. We also considered a prospective study on the use of the FactorFirst cards in terms of outcomes and patient satisfaction.