Québec – Tunisia International Partnership

From February 10 to 16, 2005, the Quebec Chapter made an evaluation visit to Tunisia in order to lay the foundations for a partnership with the Association tunisienne des hémostolies (ATH) under the twinning program set up by the World Federation of Hemophilia (WFH). After being paired with the Association sénégalaise des hémophiles (Dakar, Sénégal) in exchanges over the last five years, a partnership that led to twinning between the Dakar treatment centre and the centre in Lille, France, the CHSQ has now turned to another African nation, this one in the Maghreb region, with a population of some 10 million inhabitants.

Aline Ostrowski, Executive Director of the CHSQ, and David Page, as Vice-President of the WFH, accompanied me on my visit. Our timetable included meetings with members of the ATH, visits to the Centre national de transfusion sanguine (responsible for blood collection, safety and donation monitoring), the Institut Pasteur (responsible for the purchase and supply of blood products) and three hospitals with hematology services located in the larger cities of Tunisia (Tunis, Sousse and Sfax).

In Tunisia, health care costs are borne by the State in whole or in part through two social security funds (equivalent to our health insurance), one public and the other private, depending on whether the patient meets certain criteria ranging from employment status to civil status, and including physical condition and financial situation. During the visit, we made a number of observations, such as:

• The ATH has a dynamic Board of Directors made up of people with a variety of complementary skills —

• Hematologists, people affected by hemophilia, business people, computer and communication specialists, etc.;

• Members of the medical staff, physicians in particular, seemed very competent and dedicated — In addition, recruitment and training of physicians are not a problem, although for other health professionals it can pose certain challenges;

• Hemophilia and other bleeding disorders, von Willebrand disease in particular, are underdiagnosed — Perhaps because treatment is less frequent or less aggressive;

• Access to treatment is not uniform in all regions — Factor concentrates are only available in Tunis for all who need them, and moreover, only cryoprecipitate appears on the list of products covered by the social security funds for treatment of hemophilia A;

• The Institut Pasteur is paying too much for its factor concentrates — Perhaps due to the small volume it is buying and/or the absence of a real tendering process;

• Communication is a challenge — Three languages are spoken: Arabic
(mother tongue); French (learned at school), and Tunisian (a mixture of the two). Moreover, oral culture is predominant outside large cities owing to a fairly basic level of education and a high illiteracy rate in rural areas;

- Transportation is also a challenge — owing to the large distances, but also because of a lack of financial resources to provide transportation to Tunis where the large majority of services are located; and

- The exact number of persons affected by HIV and HCV is not known — treatment is provided for HIV, but not for HCV; these subjects are actually fairly taboo.

A number of objectives were also identified during the trip, such as the creation of a Medical and Scientific Committee in order to foster discussion among the treatment centres and standardize care, the introduction of effective government lobbying to obtain equitable access to products, setting up of a process to more efficiently track persons with bleeding disorders mainly outside the large cities, and eventually, publication of an information bulletin.

These more or less long-term goals, combined with the work that needs to be done to reach them, and a timetable, will be included in a joint plan of action soon to be drafted by the CHSQ and the ATH.

I would be remiss if I did not mention the warm welcome and hospitality the Tunisians extended to us. Special thanks must go to Islem Nafti, President of the ATH, Dr. Aicha Hafisia, the Honorary President, and Nejne Grichi, the Treasurer, for their kindness, availability and attention to our needs throughout our stay. May this partnership be crowned with success. Inch Allah!

Boutheina Said, the “physiotherapist-coordinator” for hemophilia treatment at Hôpital Rabta, in Tunis.

Volunteering at the WFH Congress 2006!

Hélène Bourgaize,
CHS Administrative Coordinator

The Canadian Hemophilia Society looks forward to welcoming the members of the global hemophilia community to Vancouver for the XXVII Congress of the World Federation of Hemophilia. The CHS is proud to be associated with the planning of this international conference and is encouraging members and chapters to participate in large numbers in this unique event. One of the key CHS responsibilities will be to ensure that support and assistance are provided to the Congress participants.

To do so, the CHS will be providing the volunteers needed to make sure that the participants with mobility problems can circulate adequately around the Congress site. Volunteers will also direct “traffic” at the social events and answer any questions participants may have.

If you are planning to participate in these four full days of scientific and psycho-social presentations, and would like to be part of the volunteer team that will be displaying friendly Canadian hospitality to the rest of the world and bringing a human touch to the overwhelming amount of information, you are the person we are looking for. Please send your name and contact information to the CHS office at hbourgaize@hemophilia.ca. More information on what is expected from the volunteers will be sent out at a later date to all those who have shown an interest in volunteering. A volunteer training session will also be offered on Sunday, May 21st, 2006.

Remember that everybody can volunteer and that a participant leaving the conference may not always remember the outcomes of a session but will always remember a friendly smile! Thank you for helping us making this event a success!

See the Hemophilia 2006 World Congress announcement on page 22.