

Canadian Hemophilia Society Report 2009-2010
to
Association of Hemophilia Clinic Directors of Canada
Canadian Association of Nurses in Hemophilia Care
Canadian Physiotherapists in Hemophilia Care
Canadian Social Workers in Hemophilia Care

Annual General Meetings, May 28-29, 2010 - St. John's, Newfoundland

Care and Treatment

Standards of care – The CHS is again providing logistical and financial support to the Canadian Hemophilia Standards Group. In 2010 we hope to finish evaluation of the *First Edition of the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders* based on the 2009 survey and begin development of the external audit process.

Support for multidisciplinary comprehensive care teams – In 2010 the CHS is again providing logistical, financial and administrative support for activities and annual meetings of nurses, physiotherapists and social workers to take place in St. John's, Newfoundland May 28-29.

Transition from pediatric to adult care – The educational toolkit on transition, including transition guidelines, for distribution to youth and their parents/guardians and other family members, and HTC's were distributed in late 2009. In 2010 the CHS is offering small grants to cover the costs of transition evenings organized by clinics and chapters.

New Team Workshop – The CHS will promote knowledge transfer from more experienced members of the HTC teams to healthcare professionals with less than three years experience. The 3rd New Team Workshop will take place in Montreal, October 1-3, 2010.

FactorFirst Program – The ER Advisory Group will adapt the *FactorFirst* card for people with rare factor deficiencies and platelet disorders.

Medical and Scientific Advisory Committee – Given the excellent organization of the 4 healthcare professional groups, the CHS Board of Directors voted in December 2009 to disband the Medical and Scientific Advisory Committee. The CHS will continue to name a Medical Advisor to the Board, one of whose roles will be to liaise with the 4 associations when medical advice is needed.

Aging with a bleeding disorder – The CHS will create a working group representing chapters and healthcare professionals to research the challenge of aging with a bleeding disorder with a view to creating a resource in 2011 and proposing a session at Rendez-vous 2011 in Calgary, May 26-29.

Research

In 2009 the CHS funded a record 9 research projects, 1 studentship and 1 research fellowship for a total investment of close to \$500,000.

The call for applications for the 2010 *Dream of a Cure* Research Program, the *Care until Cure* Research Program and the *CSL Behring – CHS – AHDCDC Fellowship in Congenital and Acquired Bleeding Disorders* closed in November, applications were evaluated by the CHS Research Peer Review Committee, and winners announced in February.

In 2010 the CHS will fund 5 research projects, 1 studentship and 1 research fellowship for a total value of over \$400,000.

The number of applications is increasing and funds are limited. The CHS was unable to invest in several research projects rated highly by the Review Committee. For details, see www.hemophilia.ca/en/research/

In addition, the CHS will develop Terms of Reference for the Research Peer Review Committee.

Support and Education

Recent workshops, conferences

- *Women & Bleeding Disorders: Life Stages* – A weekend workshop for women with bleeding disorders from the 4 Atlantic provinces, Halifax, June 12-14, 2009
- *Parents Empowering Parents (PEP) Train the Trainer workshop* – Montreal, October 23-25, 2009
- *M2 Youth Leadership Program* - A conference to develop youth skills and knowledge in fundraising, advocacy, governance, medical & scientific issues, blood products, Orford, Quebec, October 23-25, 2009
- *Drive Your Car/Drive Your Care Program* – Montreal, November 7. These one-day practical training sessions make the link between safe, defensive driving skills and prevention of bleeding and joint damage in hemophilia
- *CHS 4th National Family Inhibitor Weekend: Facing the Challenge Together* – A weekend workshop for more than 20 families, Montreal, November 13-15, 2009
- *Progress in Comprehensive Care for Rare Blood Disorders* – A conference to discuss progress in comprehensive care for patients with rare chronic blood disorders (e.g. hereditary angioedema, thalassemia...) and/or who use blood products, Toronto, November 13-15, 2009. Proceedings: www.hemophilia.ca/en/about-the-chs/collaboration/network-of-rare-blood-disorder-organizations/2009-progress-in-comprehensive-care-for-rare-blood-disorders-conference---presented-by-csl-behring/#c992

Upcoming workshops, conferences, events

- *Parents Empowering Parents (PEP) regional workshops* – 4 regional workshops in BC-Alberta (March 26-28), Saskatchewan-Manitoba (April 30-May 1), Ontario (June 4-6), Atlantic Canada (June 4-6)
- *Drive Your Car/Drive Your Care Program* events in Toronto, Vancouver and Winnipeg
- *M² Leadership Program: Walking the Talk Conference* – The 3rd national workshop for young leaders of the bleeding disorder community. This year's theme: *Smart Choices*. Fall 2010
- *Rare Bleeding Disorder Regional Workshop* – A conference to provide support and information to people with rare bleeding disorders in Western Canada, Vancouver, November 2010

Recent publications, videos

- *All About Hemophilia: A Guide for Families, 2nd Edition*
- *Cyklokapron - A Guide for Patients and their Caregivers* – A revised version of the brochure providing basic information on the uses and administration of this drug. Developed by the Canadian Association of Nurses in Hemophilia Care (CANHC).

Upcoming publications in 2010

- *Me and My Genes* – An interactive CD and on-line resource for potential carriers of hemophilia. Aimed at teens. Based on *All About Carriers*, June 2010
- *Passport to Well-Being: new module on Traveling with a Bleeding Disorder*, September 2010
- *Challenges, Choices and Decisions: Orthopedic Surgery for Patients with Hemophilia* (adaptation of original booklet for patients with inhibitors), December 2010

Awareness

- *Educational package* including a slide presentation targeted at family physicians, ob/gyns, and other hematologists about the symptoms, diagnosis and treatment of women with bleeding disorders. Developed in collaboration with the AHCDC Subcommittee on Women and Bleeding Disorders as a resource for AHCDC members to help raise awareness about women with bleeding disorders.

Safe, Secure Blood Supply

Key issues

- *Access to a safe, adequate supply of factor concentrates* – The CHS will closely follow developments in Europe and the U.S. with regard to health technology assessment and comparative effectiveness, especially with regard to prophylaxis in adults and freedom of choice in prescribing.
- *Project Recovery* – The CHS will continue to push for the recovery and manufacture of all factor VIII contained in Canadian plasma for fractionation. In early 2010, CSL began to deliver Humate P made from Canadian plasma to CBS. The remaining 70% of Canadian cryo paste is discarded by Talecris. Héma-Québec continues to receive Humate P from American-source plasma. The CHS aims to have Canadian cryo cover Canadian needs in FVIII-VWF; the surplus would be for humanitarian donations.
- *Donor deferral criteria* – CHS will continue to work to maintain the safest donor deferral criteria, and will remain involved in the *Freeman vs. CBS & Health Canada*, if appealed.

International Projects

Twinning – Twinning projects between CHS and South Africa, and between Toronto and Central Ontario Region and Jordan ended in 2009. Quebec Chapter and Tunisia have entered their final year. The CHS is exploring new opportunities for twinning beginning in 2011. A partnership between CHS and Egypt is proposed. CHS will be holding a twinning training weekend for volunteers in 2010.

Governance

Needs analysis – The CHS conducted an in-depth needs analysis of people with bleeding disorders and their families. The needs analysis included one-on-one interviews with CHS leaders and health care professionals, focus groups in 6 cities and an on-line survey of more than 500 people across the country. The results were presented to the Board in December 2009 and are now available on request.

Strategic planning – The CHS has embarked on a strategic planning exercise to develop a detailed 3- to 5-year plan for the organization. The exercise will include an environmental scan of issues which may have an impact on the bleeding disorders community; for example, health technology assessment, health care cutbacks, standards of care, and new developments in care and treatment. The CHS will also critically examine its governance structure.

Thank you!

On behalf of the CHS and its members, thank you to all the physicians, nurses, physiotherapists and social workers who donated their time and expertise to support CHS in its programming activities over the last year. We could not do what we do without you.

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