

**Canadian Hemophilia Society Report  
to  
Association of Hemophilia Clinic Directors of Canada  
Annual General Meeting, May 7-9, 2009  
Ottawa**

**Care and Treatment**

**Standards of care** – The CHS is providing financial support to the Canadian Hemophilia Standards Group to facilitate the assessment of the *First Edition of the Canadian Comprehensive Care Standards for Hemophilia and Other inherited Bleeding Disorders*

**Support for multidisciplinary comprehensive care teams** – In 2009 the CHS is again providing logistical, financial and administrative support for activities and annual meetings of nurses, physiotherapists and social workers.

**Transition from pediatric to adult care** – The CHS is leading a collaborative effort to develop an educational toolkit on transition, including transition guidelines, for distribution to youth and their parents/guardians and other family members, and HTC's.

**Rendez-vous 2009: Biennial Congress and medical/scientific symposium, Ottawa** – Again in 2009, the CHS is promoting knowledge transfer among the 4 healthcare groups and the patient organization through this meeting.

**Research**

In 2008 the CHS funded a record 8 research projects, 2 studentships and 1 research Fellowship for a total investment of close to \$500,000.

The call for applications for the 2009 *Dream of a Cure* Research Program, the *Care until Cure* Research Program and the *Novo Nordisk – 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 March.

In 2009 the CHS will fund 9 research projects, 1 studentship and 1 research Fellowship for a total value of \$500,000.

**Support and Education**

Recent workshops, conferences

- *Living with a Rare Bleeding Disorder*, a weekend workshop for patients with rare factor deficiencies and platelet disorders was held in Montreal in November 2008.
- *Women & Bleeding Disorders: Life Stages* – A weekend workshop for women with bleeding disorders from the 4 western provinces, Calgary, April 3-5, 2009

Upcoming 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
- *Families & Inhibitors* – A weekend meeting for families with children with an inhibitor, Montreal, October, 2009

- *M2 Youth Leadership Program* - A conference to develop youth skills and knowledge in fundraising, advocacy, governance, medical & scientific issues, blood products
- *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
- *Parents Empowering Parents (PEP) Train the Trainer workshop, Fall, 2009*

#### Recent publications, videos

- *Challenges, Choices and Decisions: Orthopedic Surgery for Patients with Hemophilia in the Presence of Inhibitors*
- *Bernard-Soulier Syndrome, An Inherited Bleeding Disorder*
- *Hemophilia: What School Personnel Should Know* - This new video is designed for teachers and other personnel in a school with a student who has hemophilia
- *Desmopressin: A Guide for Patients and Caregivers* – revised brochure
- *Finding Childcare for Children with Bleeding Disorders: A Parent's Guide*
- *How to Recognize and Treat Bleeds and Bruises* – A poster for daycares

#### Upcoming publications in 2009

- *All About Hemophilia: A Guide for Families*, Second Edition, December 2009
- *A Resource for Teenage Carriers*, December 2009
- *Challenges, Choices and Decisions: Orthopedic Surgery for Patients with Hemophilia (adaptation of original booklet)*, December 2009

#### **Governance**

**Needs analysis** – The CHS is currently conducting an in-depth needs analysis with people with bleeding disorders and their families. The assessment is being undertaken by a third-party consultant, Ketchum Canada Inc. The needs analysis includes 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.

#### **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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