

# 2009 Progress in Comprehensive Care for Rare Blood Disorders Conference

PRESENTED BY **CSL BEHRING**



**Network of Rare Blood Disorder  
Organizations**

**Réseau des associations vouées  
aux troubles sanguins rares**

## **CURRENT MEMBER ORGANIZATIONS:**

**Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)**

Web site: [www.aamac.ca](http://www.aamac.ca)

**Canadian Hemophilia Society (CHS)**

Web site: [www.hemophilia.ca](http://www.hemophilia.ca)

**Canadian Hereditary Angioedema Network (CHAEN)**

Web site: [www.haecanada.com](http://www.haecanada.com)

**Canadian Immunodeficiencies Patient Organization (CIPO)**

Web site: [www.cipo.ca](http://www.cipo.ca)

**Canadian Neuropathy Association (CNA)**

Web site: [www.canadianneuropathyassociation.org](http://www.canadianneuropathyassociation.org)

**Canadian Organization for Rare Disorders (CORD)**

Web site: [www.raredisorders.ca](http://www.raredisorders.ca)

**Canadian Sickle Cell Society (CSCS)**

E-mail: [thecanadiansicklecellsociety@gmail.com](mailto:thecanadiansicklecellsociety@gmail.com)

**Quebec Sickle Cell Anemia Association (QSA)**

Web site: [www.anemie-falciforme.org](http://www.anemie-falciforme.org)

**Sickle Cell Association of Ontario (SCAO)**

Web site: [www.sicklecellontario.com](http://www.sicklecellontario.com)

**Thalassemia Foundation of Canada (TFC)**

Web site: [www.thalassemia.ca](http://www.thalassemia.ca)

**The Sickle Cell Disease Parent's Support Group of Ottawa**

Web site: [www.ottawasicklecell.ca](http://www.ottawasicklecell.ca)

# Conference objectives

- Establish the foundations for the creation and implementation of national patient registries which will contribute to the understanding of rare blood disorders, help quantify how many people are affected, provide prevalence estimates, define demographics, measure treatment outcomes and facilitate research;
- Raise awareness about the need for comprehensive care for rare blood disorders;
- Share experiences, best practices and identify areas needing improvement;
- Review progress that has been made since the 2006 conference and identify the achievements;
- Evaluate what works and doesn't work in Canadian and International models;
- Advocate and push initiatives forward.