

Network of Rare Blood Disorder Organizations

Patient Registries

Chairs: Bruce Ritchie & Silvia Marchesin

Toronto, November 13, 2009



Canadian Hemophilia Society
Help Stop the Bleeding



Participating associations (2009)

Aplastic Anemia and Myelodysplasia Association of Canada
Canadian Hemophilia Society
Canadian Hereditary Angioedema Network
Canadian Immunodeficiencies Patient Organization
Canadian Organization for Rare Disorders
Canadian Association for Porphyria
Canadian Sickle Cell Society
Quebec Sickle Cell Anemia Association
Sickle Cell Association of Ontario
Sickle Cell Disease Parents' Support Group
Thalassemia Foundation of Canada



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Today's Objectives

Take a step toward developing infrastructure for rare blood disorders in Canada

a template for a national registry system – today

a national clinic structure for rare disorders - tomorrow

Support the basic triad of care, education, and research, plus surveillance

Learn from others by seeing registry examples and hearing what to do and what not to do



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We wish you an excellent day!



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