

Increasing Cohesion in a Province with 9 Hemophilia Treatment Centres through a Central Coordinator

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Objectives

Canada has 26 Hemophilia Treatment Centres (HTC). Of these 26 HTC, 9 are located in the province of Ontario. These 9 HTC are responsible for > 3300 registered patients with an inherited bleeding disorder.

In 2003 The Ministry of Health and Long Term Care (MOH) in Ontario, Canada provided funding to create the unique position of the Hemophilia Provincial Coordinator (HPC) and maintains financial support of this role to date.



The concept of an HPC role was based on the recommendation from The Canadian Hemophilia Society, Ontario Region for the formal development of Comprehensive Care Standards.

The HPC is positioned at the center of all stakeholders to facilitate communication and coordination. The HPC has an obligation to all 9 HTC in Ontario, Canada and works directly with a provincial steering committee comprised of medical directors and nurses representing each of the 9 centres and society members representing Ontario.

Methods

At the centre of communication and coordination, the HPC partners with all relevant stakeholders:

Regional

- Patients
- Hemophilia Treatment Centres/Bleeding Disorder Programs

Provincial

- Ministry of Health & Long Term Care - Blood Programs Coordinating Office
- Hemophilia Ontario
- Hemophilia Steering Committee

National

- Canadian Blood Services
- Association of Hemophilia Clinic Directors of Canada
- Canadian Association of Nurses in Hemophilia Care
- Canadian Hemophilia Society

The initial responsibility of the position was to lead the development of the Ontario Hemophilia Comprehensive Care Standards that were completed in 2005. These standards were adopted nationally in 2007 as the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders.

The HPC facilitates the use of the Canadian Comprehensive Care Standards for Hemophilia and Other inherited Bleeding Disorders by:

Identifying common priorities; program development needs; quality measures; and therapeutic services

Creating an evaluation process

Assisting clinics with the collection and utilization of data

Results

- **Facilitate** the review of the Canadian Standards with each clinic bi-annually
- **Advocate** to hospital administrators to increase HTC staffing to meet the minimum standard of care
- **Support** clinics to meet their individual short and long term goals

Improving the Standards of Care

Standardizing processes

- **Guide** the HTC to standardize CFC ordering for >500 home care patients in conjunction with >150 transfusion medicine services .
- **Organize** education events for external nursing agencies

- **Manage** the Factor Concentrate Redistribution Program resulting in the redistribution of over 2, 646,000IU and 2089mg of clotting factor concentrates.
- **Address** queries related to utilization and distribution for MOH officials.

Improving utilization of factor concentrates

Conclusions



The HPC has developed trust and credibility with the HTC, various levels of the Hemophilia Society, and the Ministry of Health and Long Term Care. The HPC is a central contact for inquiries from all said stakeholders, resulting in a streamlined approach to data gathering and problem-solving. The HPC has been instrumental in improving the standards of care in Ontario, Canada.

Acknowledgements

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