**Introduction**

Preparation of our annual report provides an opportunity for all of the 44 CANHC members to reflect on clinical care, accomplishments, collaborations, and learning over the past year. We thank the AHCDC for the opportunity to submit this report and invite those who may have questions to please contact any member of the CANHC Executive Committee.

This report is organized under the following headings:

A. Acknowledgements

B. Congratulations!

C. CANHC Membership

D. Mentorship/Training

E. Research

F. Resource Development

G. Committee Work

**Acknowledgements**

CANHC would like to make a statement of gratitude to the many groups and individuals who support us in our work and activities. We will highlight a few here:

* We acknowledge the secretarial and data entry staff who offer talent and skill that has a direct impact on the percentage of time that we can dedicate to nursing practice. We appreciate them and value their tremendous support.
* Rachel Leslie (CHS) and Annie Kaplan (AHCDC) – once again, thank you for all of the work you do to organize our meetings. It is appreciated!
* The generous support of our industry partners permits us to continue work on patient/family resource development, mentorship for our members and research activities that ultimately impact the care we provide to our patients.
* And of course, our interdisciplinary colleagues and teams, in our own clinics, and other Canadian HTCs.

**Congratulations!**

Some of our members and colleagues have had notable accomplishments and received awards this past year. A few are highlighted here:

* Catherine Sabourin had a beautiful baby girl and continues to enjoy her maternity leave. When she returns to work, she will be working part time and will not return to the Hemophilia Program. We wish her well in her new position. We welcome Tania Laflèche to the Montreal Children’s Bleeding Disorders clinic.
* Vanessa Bouskill was appointed PI (Project Investigator) at the Research Institute at the Hospital for Sick Children.
* Vanessa Bouskill was appointed Adjunct Faculty at the Lawrence Bloomberg Faculty of Nursing, University of Toronto.
* Vanessa Bouskill and Pamela Hilliard awarded CHS/Baxter Canada Inherited Bleeding Disorders Fellowship Program for Nurses and Allied Health Care Professionals. Study titled “An institutional pilot study investigating physical activity patterns in boys with hemophilia” is well under way with very interesting and important data to support individualized therapy regimes.
* Sherry Purcell received the Anne Harrington award from Hemophilia Ontario
* Dianne Bissonnette received the Hemophilia Ontario 25 years award of Devoted Service to the  Hemophilia Community

**CANHC Membership** (at time of writing)

**CANHC Members** are those who hold regular/permanent full or part time positions in a Hemophilia Treatment Centre.

**Western Region**

Kam McIntosh, RN, BSN

Colleen Buehler, RN

Erica Crilly, RN MN, NP

Caroline Farmer, RN

Deb Gue, RN, MSN

Julia Hews-Girard, RN

Nancy Hodgson, RN, BSN,

Rose Jacobson, RN

Shelina Karmali

Trudy Sale, RN, BScN

Tara Schlosser, RN BSN

Roxanne Seiferman-Nelson, RN

Carol Spitzer, RN **(chair)**

Sheri vanGunst

Celina Woo, RN NP

Dawn Zawadski, RN

**Atlantic Region**

Louise Bedard, RN **(chair)**

Dorine Belliveau, RN, BScN

Sue Ann Hawes, RN,BN

Jill MacDonald RN

Sue Van Oosten, RN, BScN

Charlotte Sheppard, RN, BN

**Ontario Region**

Kay Decker, RN **(chair)**

Diane Bissonnette, RN, BScN

Vanessa Bouskill, MN RN-ED-Peds

Georgina Floros, RN, BScN

Rebecca Goldsmith, RN

Rachel He

Lucie Lacasse, RN, MScN,

Lori Laudenbach, RN-EC, NP-Adult

Elizabeth Paradis, RN, SC

Sherry Purcell, RN

Lisa Thibeault, RN

Karen Roberts, RN (CON) BScN

Joanne Solarski

Cindy Wakefield, RN

**Quebec Region**

Claude Meilleur, RN, BScN **(chair)**

Claudine Amesse, RN, BScN

Louisette Baillargeon, RN

Diana Bolano Del Vecchio RN, BScN

Hélène Néron, RN, BScN

Catherine Sabourin, RN, BScN

Catherine Thibault, RN, BScN

**Executive – Incoming Executive for 2014 will be announced at AGM in May**

**Current executive members:**

President: Dorine Belliveau dorine.belliveau@horizonnb.ca

President Elect: Erica Crilly ecrilly@cw.bc.ca

Past President: Deb Gue dgue@provicencehealth.bc.ca

Secretary: Sheri VanGunst sheri.vangunst@albertahealthservices.ca

**Mentorship/Training**

Members engaged in several opportunities to build their knowledge and skills. Activities included conference participation, webex presentations, and mentorship visits to established bleeding disorder centers. Selected activities are as follows:

* Several new nursing staff have joined HTCs across the country. Training and orientation for each of these members has been conducted locally and, in some cases, with the assistance of CANHC members remotely.
* Participation in National Hemophilia Foundation Congress
* Participation in ISTH as:
	+ Congress delegates
	+ Podium presentations and poster presentations by members
* Participation in NACCHO – Hemophilia Camp Meeting
* Participation APHON meeting in Halifax
* Mentorship visit to St Justine hospital by Saint John, NB clinic.
* CANHC Fall Education Meeting
* Orientation and Training for other Health Care Providers (i.e. GPs; ER staff; nursing unit staff, transfusion medicine and lab staff.
* Webex and Industry sponsored presentations
	+ Claude Meilleur for CSL Behring and Octapharma

**Research**

CANHC recognizes both strengths and areas that need development in our collective research skills. We continue to utilize the expertise of Leanne Currie from UBC School of Nursing.

This list is not exhaustive; however we wanted to share some of our activities as follows:

* CANHC Journal Club – This initiative would not be possible without the dedication of our coordinator: Sheri van Gunst (Calgary) we also acknowledge the support and mentorship of Dr. Leanne Currie.
	+ Journal Club Presenters included: Erica Crilly, Sheri vanGunst, Dorine Belliveau, Celina Woo, Georgina Flores
	+ Dental survey: practice patterns

Abstract Submissions and Poster Presentations

* Bayer Nursing Symposium, Berlin Germany, May 2013. Bouskill, V., Carcao, M., Blanchette, V., Hilliard, P., Wakefield, C. A Canadian Experience with a Newly Diagnosed Severe Hemophilia A Male with High Titer Inhibitor Development.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Floros, G., Kaplan, A., Cottingham, D., Lewis, J., Wakefield, C., Crymble, S., Bouskill, V. An Evaluation of a Canadian Transition Program: From Pediatrics to Adult Care.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Bouskill, V., Carcao, M., Blanchette, V., Wakefield, C. Evolving the Pediatric Homecare Infusion Program: A Canadian Experience.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Bouskill, V., Kumar, R., Craik, A., Whitney, K., Zhang, C., Schneiderman, J., Carcao, M. Comparison of increase in FVIII levels with exercise and DDAVP challenge: results from the SickKids Hemophilia exercise study.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Rizzi, M., Bouskill, V., Wakefield, C., Stain, AM., Carcao, M. FIX levels in an unselected population of mothers of Haemophilia B patients.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Semple, L., Pritchard-Kennedy, A., Bouskill, V., Karasevich, J., Riske, B., van Gunst, S. Don’t Push Your Luck! Evaluation of Evidence-Based Educational Board Game for Children Living with Hemophilia.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Avila, M., Bouskill, V., Rand, M., James, P., Carcao M. Repair of a bicuspid aortic valve resolved the acquired von Willebrand syndrome in a 17 year-old boy: Bleeding was the only indication for surgery.
* World Federation of Hemophilia, Melbourne Australia, May 2014: K. Decker, K. Nagel, AK. Chan. What is known about care of a newborn with hemophilia?
* World Federation of Hemophilia, Melbourne Australia, May 2014: K. Decker, K. Nagel, AK. Your Inhibitor Treatment Plan and You: Is your treatment working for you?
* World Federation of Hemophilia, Melbourne Australia, May 2014: Nagel K, Decker K Goldsmith R, Chan AK: Pharmacokinetics of recombinant and plasma-derived factor IX products in pediatric patients with severe hemophilia B
* World Federation of Hemophilia, Melbourne Australia, May 2014: Lori Laudenbach: Hemophilia Summer Camp: Learning Through Fun & Games in a Digital World
* World Federation of Hemophilia, Melbourne Australia, May 2014: Lori Laudenbach: Compartment Syndrome in an Undiagnosed Adolescent with Mild Hemophilia A: Urgent Need for a Collaborative Team Approach for Short and Long Term Care
* World Federation of Hemophilia, Melbourne Australia, May 2014: Thibeault, L., Bissonnette, D. Comparing Similar and Diversified Treatment Modalities in Hemophilia Patients with Post-Operative Dental Complications.
* World Federation of Hemophilia, Melbourne Australia, May 2014: Floros, G. The creation and implementation of a nursing fellowship in bleeding disorders
* World Federation of Hemophilia, Melbourne Australia, May 2014: Floros, G., He, R., Anderson, M.  Continuous Quality Improvement for Continuous Factor Infusion
* World Federation of Hemophilia, Melbourne Australia, May 2014: Crymble, S., Higgins,T., Floros, G. Three roles, one magnificent outcome: the organizational successes of an integrated camp experience in Ontario, Canada.
* World Federation of Hemophilia, Melbourne Australia, May 2014:  Crymble, S., Anderson, M.,  Floros, G.,  Travas, A., Teitel, J. A provincial redistribution system to prevent wastage of clotting factor concentrates:   6.5 year update
* World Federation of Hemophilia, Melbourne Australia, May 2014: Woo, Celina, Crilly, Erica, and Wu, J. A single centre experience with venous access devices in pediatric Hemophilia A patients with inhibitors".
* Ho, S., Gue, D., McIntosh, K., Bucevska, M., Yang, M. and Jackson, S. (2014), An objective method for assessing adherence to prophylaxis in adults with severe haemophilia. Haemophilia,
* WFH 2014 World Congress.  McIntosh, K. “Individualization of prophylaxis in adults improves bleeding outcomes”.  Poster pending
* Thibeault C., Corchetière C., Francoeur D., David M. Rivard GE., Winikoff R.: Multidisciplinary care for women; virtual made real
* Teaching Self infusion using the KidK kit in the Camp Setting, VanOosten, S
* Self infusion: Becoming independent when there is an added Challenge, VanOosten, S

**Resource Development**

CANHC has had a long history of developing educational and support resources for patients and families, as well as health care providers. This is accomplished through CANHC-lead initiatives, and through collaboration with stakeholder groups. Some of our activities are summarized below:

* Redevelopment of the Hospital for Sick Children and St Michael’s Hospital Transition Program – improving the transition of youth and lost to follow up rates.
* The Hospital for Sick Children, with the financial support of Baxter, developed a homecare infusion DVD – both port-a-catheter access and venipuncture access. To be available for parents and patients to review while at home during the learning process of homecare.
* Review and revision of rare factor deficiencies booklets (Quebec Nurses): ongoing
* Other Publications:
	+ CHS-Q Newsletter
	+ Hemophilia today
* Workshops and Programs
	+ Aging with a bleeding disorder
	+ Code Rouge
	+ Family weekend event: presented on women and bleeding disorders.
	+ Guys Getaway
	+ Education Session for Rural Patients
	+ Organizing and facilitating the W2 women’s conference.
	+ Charting your Course and Hemophilia Management
	+ Tween Drop In/Self-infusion Clinics
* Camps: Supported each year on a regional basis
* CANHC has developed an independent website canhc.org to promote resource sharing among colleagues, and a more efficient approach to managing our organization. This site is currently for members only.

**Committee Work - Local and National**

* CANHC contributes nursing expertise and consultation in a variety of groups at the local, national, and international level. Some examples are listed as follows:
* CHS Programs Committee – Charlotte Sheppard
* CHS Blood Safety Committee – Diane Bissonnette, Julia Hews-Girard
* CHS Aging Working Group – Lucie Lacasse
* CHS Women and Bleeding Disorders Working Group – Sherry Purcell, Claudine Amesse, Catherine Thibeault
* CBS FVIII Utilization Working Group – Deb Gue, Diane Bissionnette
* CHS Care and Treatment committee -Erica Crilly
* CHARMS Committee – Claude Meilleur and Charlotte Sheppard
* CHS Research Committee - Trudy Sale
* CHS national youth committee - Georgina Floros

**Conclusion**

In conclusion, as always, we look forward to the coming year and the continued opportunity to offer the best comprehensive care possible to the Bleeding Disorders Community.

On behalf of the CANHC Members:

Respectfully submitted by,

**Dorine Belliveau** **Erica Crilly**

CANHC president CANHC president-elect

Moncton Vancouver

**Deb Gue** **Sheri** **VanGunst**

CANHC past president CANHC Secretary-Treasurer

Vancouver Calgary