**Annual Report – May 2014**

The Canadian Physiotherapists in Hemophilia Care (CPHC) are pleased to report our activities for the past year. Our members continue to provide expertise physiotherapy care to people with bleeding disorders through our participation in the multi-disciplinary clinic, educational sessions and through research. In addition to our local and national involvement, CPHC members contribute at an international level to improve global access to physiotherapy care.

**Physiotherapy Care within the Comprehensive Clinics:**

The members of the CPHC are committed to providing quality physiotherapy care within the comprehensive care clinics. Over the last year our group continues to struggle with inadequate funding of physiotherapy allocation within the clinics. Although we have physiotherapists dedicated to each of the hemophilia treatment centres, many physiotherapists do not have hospital or dedicated funding to allow their full participation as members of the multi-disciplinary team for annual reviews, acute bleed management and rehabilitation. Also, due to the lack of institutional support in some centres, CPHC members are limited in their ability to attend our CPHC Annual General Meeting, CHS Rendez-Vous and other educational events.

**Hemophilia Clinic, Provincial and National Education:**

Our members are active participants in local and provincial education programs including inhibitor workshops, “Just the Guys” weekends, chapter meetings, family weekends and camps including the following:

Atlantic Provinces Pediatric Hematology Oncology Network: Hemophilia Day. Halifax, November 2013. Carolyn Jarock (Halifax), Colleen Jones Down (St. John’s), Kathy Mulder (Winnipeg), Greig Blamey (Winnipeg).

Colleen Jones Down (St. John’s)

* November of 2013: Educational Session to local health care providers on the role of physiotherapy and acute bleed assessment and management. Twillingate, Newfoundland.
* Physiotherapy Inservices: CHS Local Chapter Summer Camp, Newfoundland.

Mary Jane Steele (London)

* Onsite Physiotherapist, Overnight LIT leader: SWOR Summer Camp
* Provincial Family Camp Planning Committee

Nichan Zourikian (Montreal)

* 2013 World Hemophilia Day - CHU Sainte-Justine Hem-Onc department presentation : ‘Saignements musculo-squelettiques : Quoi faire après le remplacement de facteur et pourquoi?’ (MSK bleeds : What next – after factor replacement?)

We are regular contributors to Hemophilia Today and in the Spring 2014 edition Lawren De Marchi (Vancouver) provided an article “No pain, no gain? Dispelling five common pain myths.”

Web ex continues to be a valuable tool for national educational experiences. With the generous support of Baxter Canada, Karen Strike (Hamilton) organized and facilitated a web-ex presentation by Cathy Walker (Kingston) on “Specialization/Special Interest Group Options for Physiotherapists in Hemophilia Care.”

We continue to benefit from the support of Bayer Inc. to provide a mentorship program to physiotherapists new to hemophilia care. We believe this mentorship encourages the development of expertise in hemophilia care. In 2014, JoAnn Nilson (Saskatoon) hosted Elia Fong (Edmonton) and Erin McCabe (Edmonton) and Sandra Squire (Vancouver) hosted Laurence Boma Fischer (Toronto).

Several of our members including Lawren De Marchi (Vancouver), Sandra Squire (Vancouver), Karen Strike (Hamilton), Nichan Zourikian (Montreal), Pam Hilliard (Toronto), and Laurence Boma Fischer (Toronto) participated in the Pfizer Canadian Ultrasound Initiative December 2013, Montreal.

Kathy Mulder (Winnipeg) was interviewed by Dr. Poon and Dr. Card for her perspective on the “History of Hemophilia in Canada.”

Karen Strike (Hamilton) was awarded the Hamilton Health Sciences Clinical Health Professional Research Award for 0.4 FTE support for two years to provide support for her research in hemophilia care.

**Research Projects:**

CPHC members are actively participating in and conducting research to improve outcomes for patients with bleeding disorders. Please see the attached Appendix for details of the publications from 2013.

Ongoing involvement in research projects include:

The Canadian Hemophilia Escalating Dose Prophylaxis Study (CPHS), Principal investigators Dr. V. Blanchette and Dr. B. Feldman

Greig Blamey

* Investigating the attitudes & practices of Canadian Physiotherapists towards sexual health in hemophilia

Pam Hilliard (Toronto) continues to be involved in several research projects including:

* An Institutional Pilot Study to Investigate Physical Activity Patterns in Boys with Hemophilia, Bouskill V, Hilliard P; Awarded Baxter-Canadian Hemophilia Society Inherited Bleeding Disorder Fellowship Program for Nurses and Allied Health Professionals 2013
* Novel Imaging Techniques for Assessment of Early Cartilage and Soft Tissue Changes in Hemophilic Ankles PI Dr. Andrea Doria, Funded by CHS (second year of funding)

Kathy Mulder (Winnipeg)

* Is there a relationship between increased Body Mass Index and hemophilic arthropathy in Canadian children with severe Hemophilia A

JoAnn Nilson (Saskatoon)

* Evaluate the effectiveness of “HIRT?” Hemophilia Injury Recognition Tool, for young men with mild hemophilia. Webinar Presentation April 24, 2014.
* Pain management in older men with hemophilia, Saskatchewan program project
* Health Science Master’s Student: Thesis project: Effectiveness of the self-management assessment tool specifically developed for young men with mild Hemophilia

JoAnn Nilson (Saskatoon) and Kathy Mulder (Winnipeg)

* Bayer Caregiver Award: Development of self-assessment tool for young men with mild hemophilia
* BHAP Global webinar participation with Mild Hemophilia Research. Development of a self-management smart phone application for young men with mild hemophilia. Feb 18, 2014.

Karen Strike

* Bayer Caregiver Award: An interactive educational website for certification in home infusion: musculoskeletal module.
* Bone Mineral Density in Canadian Boys with severe hemophilia A or B, a cross sectional, observational study. PI Cecily Bos, Dr. Anthony Chan

Karen Strike (Hamilton) and Sandra Squire (Vancouver)

* Physiotherapy and point of care ultrasonography for the assessment and management of acute hemarthrosis. Strike K, Chan AK, Iorio A, Lawson W, Jackson S, Squire S.

Sandra Squire (Vancouver)

* Individualization of prophylaxis in adults improves bleeding outcomes.McIntosh K, Squire S, Bartholomew C, Camp P, Jackson S
* Physical Activity in Adults with Severe Hemophilia: A Feasibility Study. Squire S, Jackson S, Camp P

Nichan Zourikian (Montreal)

* Once-a-day-prophy/QoL study in young adult PWH. PI Dr. Jean St. Louis

Kathy Mulder (Winnipeg) and Karen Strike (Hamilton) are authors on a Cochrane Collaboration Project on Exercise and Hemophilia (protocol phase) in partnership with Vellore, India.

Nichan Zourikian (Montreal) and Karen Strike (Hamilton) are invited reviewers for the Journal of Thrombosis and Hemostasis. Nichan is also an invited reviewer for the Hemophilia Journal.

**Conferences:**

We continue to strengthen our relationship with the American Physiotherapy Working Group of the National Hemophilia Foundation (NHF) and Karen Strike (Hamilton) was generously sponsored by Pfizer Canada to attend the NHF meeting in Anahiem, California, October 2013.

World Federation of Hemophilia Musculoskeletal Congress, Chicago 2013: CPHC were strongly represented at the Congress and would like to thank Bayer Inc for their generous support.

Nichan Zourikian (Montreal) was co-presenter during symposium- *How we manage inhibitor patients with musculoskeletal problems: a continuous patient journey:* Physiotherapist’s role in management of PWH pre-post elective orthopedic surgery and a free paper session co-chair. Nichan was also a judge for the Horoszowski Best Free Paper Award.

Greig Blamey (Winnipeg) was a session co-chair for the live orthopedic surgery session and moderated the interdisciplinary panel of experts.

Nichan Zourikian (Montreal) and Greig Blamey (Winnipeg) were presenters/debaters on the Crossfire Session: Ice vs. No Ice.

Karen Strike (Hamilton)

* Strike K, Nixon J, Graham N, Jarock C, Squire S, Van Neste C. Building evidence into practice: proposed evidence based updates to the Canadian physiotherapists in hemophilia care (CPHC) standards of care.

Accepted as poster presentation WFH Musculoskeletal Congress, Chicago 2013.

* Strike K, Almonte T, Chan AK, Decker K, Goldsmith R, Iorio A, Matsui N, Smith F, Walker I, Waterhouse L. Interdisciplinary musculoskeletal clinic for persons with inherited bleeding disorders.

Accepted as poster presentation WFH Musculoskeletal Congress, Chicago 2013.

World Federation of Hemophilia 2014 Annual Congress: The CPHC would like to thank Pfizer Canada, Bayer Inc. and Novo Nordisk for their generous support of our members. The CPHC is very proud of the original research, abstracts, posters and oral presentations that will be presented by our members at the Congress:

Hilliard P, Abad A, Feldman BM, Funk S, Manco-Johnson M, Petrini P, van der Net J, Zourikian N, and Blanchette VM. Global utilization of the International Prophylaxis Study Group (IPSG) Physical Therapy Education Web-site Module

Accepted as poster presentation WFH Congress, Melbourne May 2014

Souza FMB, Mello MHM, Matta MAP, Silva JBJ, Lima EO, Nunes LTN, Carneiro JDA, Villaca PR, Zourikian N, Hilliard P. Brazil Hemophilia Joint Health Score version 2.1 Reliability Study

Accepted as oral presentation WFH Congress, Melbourne May 2014

Carneiro JDA, Ozelo MC, Villaca PR, Antunes SV, Brandao LR, Young NL, Hilliard P, Abad A, Blanchette VS, Feldman BM. Comparison of persons with hemophilia in the developing (Sao Paulo, Brazil) and developed world (Toronto, Canada) : A cross-sectional study

Accepted as oral presentation WFH Congress, Melbourne May 2014

Souza F, Mello M, Tanaka C, Zourikian N, Hillard P, Abad A, Villaça P, Carneiro J

Correlation between the Hemophilia Joint Health Score (HJHS 2.1) and the number of previous joint bleeds in children with hemophilia: preliminary results.

Accepted as poster presentation WFH Congress, Melbourne May 2014

Nilson J, Mulder K. Development of an app for smart phone for young men with mild hemophilia.

Accepted as oral free paper presentation WFH Congress, Melbourne May 2014.

Strike K, Smith F, Chan AK, Almonte T, Chaston C, Decker K, Goldsmith R, Matsui N, Orschel C, Walker I, Waterhouse L, Iorio A. Assessment of patient preferences and perceived value of the comprehensive interdisciplinary combined hemophilia and orthopedic clinic using a validated questionnaire.

Accepted as a moderated oral poster WFH Congress, Melbourne May 2014.

Strike K, Chan AK, Lawson W, Squire S. Physiotherapy and point of care ultrasonography in the management of hemophilia: training phase.

Accepted as a free paper oral presentation WFH Congress, Melbourne May 2014.

Matsui N, Orschel C, Strike K. The use of custom orthoses (braces) for pain management in hemophilic arthropathy: two case studies.

Accepted as poster presentation WFH Congress, Melbourne May 2014.

McIntosh K, Squire S, Bartholomew C, Camp P, Jackson S. Individualization of prophylaxis in adults improves bleeding outcomes.

Accepted as poster presentation WFH Congress, Melbourne, 2014.

Squire S, Jackson S, Camp P Physical Activity in Adults with Severe Hemophilia: A Feasibility Study.

Accepted as poster presentation WFH Congress, Melbourne, 2014.

**International Activities:**

Pfizer Global Hemophilia Summit: Karen Strike (Hamilton), Sandra Squire (Vancouver) and Nichan Zourikian (Montreal) were invited to attend the European Ultrasound Preceptorship in Potsdam Germany, September 2013.

Novo Nordisk Hemophilia Exchange Program: Karen Strike (Hamilton) visited the Beijing Comprehensive Hemophilia Treatment Centre, China, November 2013.

Greig Blamey (Winnipeg) participated in several international activities including:

* WFH Orthopedics workshop (combined PT/ortho surgery) in Kiev, Ukraine
* Member of the HERO International Advisory Board and the HERO Canadian Advisory Board
* Invited Speaker - Irish Haemophilia Society Annual Meeting

Kathy Mulder (Winnipeg) continues to be active on the world stage as a member of the WFH Twinning Committee.

Nichan Zourikian (Montreal) was invited to present at the 2013 NHF Inhibitor Summits: Nashville, Seattle. Nichan also provided mentorship to a physiotherapist from Belgium.

In closing, we would like to take this opportunity to thank the AHCDC, CANHC, CSWHC and CHS for your continuing support and collaboration with the CPHC to improve care for patients with bleeding disorders. We are also thankful for the support we receive through our industry partners: Bayer, Baxter, Novo Nordisk, CSL Behring, Pfizer, Octogen and Octopharma. As this report indicates the CPHC is a very involved, productive and dynamic group. We look forward to an exciting year in which we can continue to strengthen our role through direct patient care, education and research within our interdisciplinary treatment teams.

Respectfully submitted,

Sandra Squire Karen Strike

President, CPHC Vice-President, CPHC

**Appendix: List of Publications:**

Chen, L., Sun, J., **Hilliard, P**., **Zourikian, N**., Hang, M., Blanchette, V., Poon, M.-C. and Luke, K. (2013), ‘Train-the-Trainer’: an effective and successful model to accelerate training and improve physiotherapy services for persons with haemophilia in China. Haemophilia 2013:1-5.

Forsyth, A. L., **Zourikian, N**., Rivard, G.-E. and Valentino, L. A. (2013), An ‘ice age’ concept? The use of ice in the treatment of acute haemarthrosis in haemophilia. Haemophilia, 19: e393–e396. (Early view, published online Oct 2013)

**Hilliard P, Zourikian N**, Blanchette V, Chan A, **Elliott B**, Israels SJ, **Nilson J**, Poon M-C, Laferriere N, **Van NesteC**, **Jarock C**, Wu J, McLimont M, Feldman B. Musculoskeletal health of subjects with hemophilia A treated with tailored prophylaxis: Canadian Hemophilia Primary Prophylaxis (CHPS) Study. [J Thromb Haemost.](http://www.ncbi.nlm.nih.gov/pubmed/23301594##) 2013 Mar;11(3):460-6.

Kumar R, Stain AM, **Hilliard P**, Carcao M. Consequences of delayed therapy for sports-related bleeds in patients with mild-to-moderate haemophilia and type 3 von Willebrand’s disease not on prophylaxis. Haemophilia 2013:1-3

Sun, J., **Hilliard, P. E**., Feldman, B. M., **Zourikian, N**., Chen, L., Blanchette, V. S., Luke, K. H. and Poon, M.-C. (2013), Chinese Hemophilia Joint Health Score 2.1 reliability study. Haemophilia 2013 :1-6