



## **Canadian Social Workers in Hemophilia Care (CSWHC) Annual Report – May 2013**

### **MEMBERSHIP:**

Co-chairpersons: Anne Vaughan (2013-2015) and Patty Phrakonkham-Ali (2012-2014)  
Past co-chairperson: Claude Bartholomew

There continues to be changes within our social work group due to movement within individual's department and medical leaves but there are 20 social work position assigned to work with the Bleeding Disorders Clinic across Canada. With the much appreciated support of the CHS and the supporting pharmaceutical companies, 9 members of the CSWHC group met at Rendezvous 2013 in Winnipeg, Mb in May 2013. Anne Vaughan was unable to attend but was able to join via teleconference.

### **CSWHC and CHS:**

#### CHS Committee support

Social work has maintained representation on most of CHS committees and initiatives including the Program Committee, Medical Symposium Planning Committee, Rare Bleeding Disorders Committee, Aging and Hemophilia Committee, Parents Empowering Parents Committee, the New Team Workshop, in addition to working within their own centers to better represent and advocate for services for people experiencing bleeding disorders and their families.

#### Hemophilia Today

Social work continues to provide articles for Hemophilia Today newsletter and has participated with CHS' Clinic Review that took place this past year, to be completed in 2014.

#### Parents Empowering Parents (PEP)

PEP continues to be one of our major initiatives. The first CHS national PEP committee was formed in 2013 with representatives from parents, social workers, nursing and physiotherapy and is co-chaired by Anne Vaughan and Michelle Simms. A Program Committee proposal was prepared and successful in 2013. One parent was funded to attend the PEP International meeting scheduled for winter 2014 in addition to Michelle Simms, who secured her own funding to represent Canada. PEP sessions were held in Manitoba and Alberta in 2013. The Halifax treatment centre piloted a "mini" PEP in October in conjunction with clinic. The PEP committee continues to explore ways of making workshops more accessible and affordable. Workshops are planned for Saskatchewan, Ontario and Atlantic Canada in 2014. In addition, PEP has been added to the CHS website and efforts are being made to develop a PEP community within CHS, including all trained PEP facilitators, staff and all parents who have attended PEP in the past.

**REVERSE PAGE**

All workshops are led by CSWHC social workers and trained facilitators. Connie Shrubsole has agreed to chair the PEP Curriculum Working Group comprised of one parent and three social workers. A second working group on evaluation is planned for 2014.

### **ACCOMPLISHMENTS:**

- CSWHC has liaised with the Youth Committee and developed a Vocational Assessment Tool that is now available on CHS' intranet site.
- Our Social Work members are also actively engaged and involved with their clinics on educational and outreach clinics, and research on issues identified from the HERO National Study. A research proposal was submitted for the CHS-Novo Nordisk Psychosocial Research Program by Claude Bartholomew and Linda Waterhouse to look into quality of life and vocational experiences of moderate and severe male hemophiliacs.
- Another member, Michelle Sims, has her poster abstract on "Pain Management: Do We Offer Appropriate Care for Men with Pain Due to Hemophilic Arthropathy" accepted to WFH Congress and will be attending Congress 2014. Michelle also leads Men and Pain – research focus group series – Nov. 29/13, March 29/14 with a third planned to follow. She also organized a panel of consumers for their Annual Planning Day with the theme of pain management. The SK Bleeding Disorders Program was awarded a Leading Practice Award from Accreditation Canada (one of 5 in the Saskatoon Health Region).
- Hulda Niv represented CSWHC at the Rendezvous 2013 and presented at the medical symposium on "Occupation and Social Adaption among Hemophilia Population". Hemophilia Story: In May 2013 Hulda wrote a story about her experience with a hemophilia patient. This story is part of a collection of stories that was published as a book in November 2013 by the American SW Group. Hulda also wrote an article for Hemophilia Today: Hemophilia and Career Decisions: Future outlooks, Aug. 2013.
- Several social workers presented the HERO study results to HCT members for great psychosocial focused discussions.

### **ON-GOING PROJECTS:**

Connie Shrubsole continues to lead our Journal Club and several members sit on the PEP Steering Committee.

CSWHC is committed to continued learning and growth and will be exploring developing our own Constitution and further explore the topic of professional development on sexuality and pain management.

Thanks again to CHS, provincial chapters and to our pharmaceutical partners for their much appreciated support.

Respectfully submitted by:

Patty Phrakonkham-Ali, RSW and Anne Vaughan, BA, MSW, RSW