



Canadian Hemophilia Society  
Help Stop the Bleeding  
Société canadienne de l'hémophilie  
Arrêtons l'hémorragie

## REPORT TO THE ASSOCIATION OF HEMOPHILIA CLINIC DIRECTORS OF CANADA (AHCDC)– SPRING 2014

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### CARE AND TREATMENT

**Standards of care** – To gather data on bleeding disorder treatment centre resources, the CHS developed a centre assessment procedure which was launched in late 2013. The assessment procedure is supported by the AHCDC. All the centres but one indicated their willingness to participate. As part of the assessment, a patient satisfaction survey was mailed to a random cross-section of patients by participating centres. Interviews with comprehensive care team staff are being conducted and will be completed by the end of April 2014. (The Quebec Chapter had previously conducted similar interviews.) Individual reports for each centre and a national report will be prepared this summer.

**Support of annual activities of CANHC, CPHC and CSWHC** – The CHS is providing funding and logistical support for annual and regional meetings of the nursing, physiotherapy and social work groups and for health care provider projects.

**CHARMS 2.0** – The CHS led the creation of the *Clotting Factor Concentrate Utilization Working Group* with AHCDC, CANHC, CBS, Héma-Québec and others to develop a fully integrated national information system to replace the current version of CHARMS, Helitrax and EZ-Log. A number of meetings were held between October 2012 and July 2013. A business case was submitted by CBS to the provinces and territories in summer 2013 but no response to the funding request has been announced. CHS staff and volunteers participated in final testing of the patient home infusion reporting module that is part of iCHIP, being developed by the BC Provincial Blood Coordinating Office and officially launched in April 2014.

**Access to latest drug therapies** – The CHS has published articles on new HCV drugs and clotting factor concentrate pipeline products in *Hemophilia Today* and on the Web site.

**Rendez-vous 2013** – This event, held in Winnipeg from May 24-26, provided networking, training and development opportunities to more than 130 members of the health care teams from the 25 treatment centres across the country: physicians, nurses, physiotherapists and social workers. Over 80 patients and their families also benefited from the medical symposium presentations as well as the community development workshop which focused on 60 years of evolution in care and what lies ahead for the next ten years. It also looked at what the CHS has accomplished halfway through its 2011-2015 strategic plan.

**CODERouge** | **WHEN WOMEN BLEED TOO MUCH** – Several activities have been organized by **CODERouge** ambassadors across the country. Among these activities, the presence of **CODERouge** booths at the Edmonton's Woman Show on March 2 and 3 and the PEI Women's Health and Wellness Expo held on September 28 were significant highlights. Various

presentations were also made in Ontario, Alberta and New Brunswick. **CODERouge** ambassadors also raised awareness in Winnipeg and Calgary during blood drives and other events, and the **CODERouge** flyer was reprinted and over 4,000 of the flyers have been distributed over the last year.

To further the **CODERouge** mission, the CHS chapters with staff made a commitment to enhance their support to their regional **CODERouge** ambassadors. This support will include teleconferences to discuss events which could be attended or organized as well as actions to take in order to increase awareness.

The CHS continues to develop a cause-related marketing campaign to increase awareness about bleeding disorders in women. This campaign will use an e-novella about a woman who bleeds too much, social media and a self-administered bleeding score quiz to reach undiagnosed women across the country.

**VWD awareness** – The plan to partner with the Society of Obstetricians and Gynaecologists of Canada (SOGC) to revise the 2005 SOGC Guidelines on the Gynaecologic and Obstetric Management of Bleeding Disorders in Women and promote the new guidelines through CMEs has been delayed by management changes at the SOGC.

For the upcoming year, the CHS has registered as an exhibitor for four major medical conferences: the National Emergency Nurses' Affiliation Pan-American Conference (April 27-29 in Toronto), the Canadian Association of Emergency Physicians Annual Conference (May 31-June 4 in Ottawa), the 70th Annual Clinical and Scientific Conference of the Society of Obstetricians and Gynaecologists of Canada (June 10-13 in Niagara Falls) and the 2014 Family Medicine Forum of the College of Family Physicians of Canada (November 13-15 in Québec City).

## EDUCATION AND SUPPORT

**Passport to well-being** – With Bayer as the new sponsor of the *Passport to well-being* program, the five updated and rebranded modules benefitted from a new look in 2013. Still to come is the revision of the *Charting your course* module. In 2014 a seventh module on patient rights and responsibilities is planned.

**Hemophilia Today** – The last three issues were published in August 2013 (**RENDEZ-VOUS 2013**); November 2013 (**RESEARCH**) March 2014 (**GENERAL**). Due to new memberships, the number of hard copy subscriptions increased by 16% in 2013. Many new members have opted for electronic access to *Hemophilia Today*.

**Web site** – From January through December 2013, the CHS Web site received, on average per month, 14,875 unique visitors, 17,815 visits and 35,587 page views. This is consistent with 2012 traffic.

**Rare inherited bleeding disorders** – Revision of information booklets on glanzmann thrombasthenia, factor VII deficiency and factor XIII deficiency in collaboration with the Quebec nurse coordinators and the AHDCDC Sub-committee on Rare Bleeding Disorders is completed; the booklets will be released early in 2014.

**Ageing with a bleeding disorder** – Over the last year, regional workshops on ageing with a bleeding disorder were held at TCOR, SWOR, The Manitoba Chapter and the New

Brunswick Chapter. Model workshop materials developed by chapters have been uploaded on the CHS intranet for use by other chapters. In addition, two articles were published in the Sage Page section of *Hemophilia Today* in March and November.

**Parent Support** – Manitoba held a *Parents Empowering Parents* (PEP) workshop over two sessions in April and May 2013. Alberta held a PEP weekend workshop in October 2013 and Nova Scotia piloted a PEP workshop in conjunction with their clinic, with one session held in October 2013 and the second to be held in April of 2014.

**James Kreppner Memorial Scholarship and Bursary Program** – Seventeen (17) applications for scholarships, bursaries and mature student bursaries were received and reviewed by the *James Kreppner Memorial Scholarship and Bursary Program* Review Committee. Two academic scholarships, one bursary and one mature student bursary were awarded in 2013.

**Network of Rare Blood Disorder Organizations (NRBDO)** – Two face-to-face meetings were held. The first was held in March 2013 at Héma-Québec in Montreal. With a view to making the NRBDO more independent of the CHS, a strategic plan was developed, funding was sought for a part-time support staff, and a NRBDO Web site and e-mail address were created separate from the CHS server. The second meeting was held November 9-10, 2013 in Toronto to follow-up on the NRBDO Action Plan. It was decided to proceed with the hiring of a part-time support staff. The NRBDO is at an important crossroad in its history and on its way to being self-sufficient and independent from the CHS support which it has received for the last 10 years.

**Youth Activities** – The first annual e-newsletter promoting youth activities (nationally and provincially) was developed in fall 2013. This newsletter was posted on the Web site and circulated by the chapters and clinics. A **Youth Leadership Workshop** focused on psychosocial issues was held at the Me to We Leadership Centre in Bethany, Ontario from September 13-15, 2013. Twenty-six young adults from across the country participated in this event.

**Chapter Relations** – To increase volunteer knowledge around CHS tools, governance, policies and other practices, a workshop called *National Chapters: Working More Cohesively* was offered in conjunction with *Rendez-vous 2013*. In addition to the Workshop, A Chapter Reference Manual which includes 13 sections is now available in both English and French on the CHS intranet and is accessible to all provincial and regional staff and volunteer leaders.

A successful Education Workshop took place in Vancouver on April 27. Over 50 adults and 20 children participated in this one-day event.

## RESEARCH

The call for 2014 research programs was launched at the end of August with a deadline for applications of November 15. The 2014 CHS *Dream of a Cure* Research Program received 3 research proposals and 3 studentship applications, the CHS – *CSL Behring – AHDCDC Fellowship in Congenital and Acquired Bleeding Disorders* received 2 proposals, the *Pfizer Care until Cure* Research Program received 2 proposals, and the *CHS – Baxter Fellowship for Nurses and Allied Health Care Providers* received 5 proposals. The newly

created *CHS – Novo Nordisk Psychosocial Program* received 1 proposal. Applications will be evaluated by the CHS Research Peer Review Committee and winners will be announced in March 2014. Over half a million dollars will be invested in research in 2014.

In 2013 the CHS funded three **DREAM OF A CURE** research projects (including two second-year projects) and three studentships:

*Oral administration of FVIII DNA to modulate inhibitors in hemophilia mice*

Second-year funding

Dr. Gonzalo Hortelano, Department of Pathology and School of Biomedical Engineering, McMaster University, Hamilton

*Platelet-type von Willebrand disease: Novel studies in the PT-VWD mouse model*

Second-year funding

Dr. Maha Othman, Biomedical and Molecular Sciences, Queen's University, Kingston

*Incorporation of rFVIII into platelets as a potential therapy in patients with inhibitory antibodies to factor VIII*

First-year funding

Dr. Walter Kahr, Program in Cell Biology, The Hospital for Sick Children, Toronto

#### LAB-WORK STUDENTSHIPS

*Investigating the influence of SNPs (Single Nucleotide Polymorphisms) on variability of the Type 2B VWD phenotype*

Malak Elbatarny, under the supervision of Dr. Paula James, Queen's University, Kingston

*The effect of FVIII on complement system activation*

Joshua Foley, under the supervision of Dr. Ed Conway, University of British Columbia, Vancouver

*In-vitro clotting assays measuring equivalent concentration of FEIBA and rFVIIa*

Xena Li, under the supervision of Dr. Howard Chan, McMaster University, Hamilton

In 2013 two **CARE UNTIL CURE** research projects were funded with support from Pfizer:

*Assessing differential immunogenicities of factor VIII molecules: Do previously treated hemophilia A patients represent a valid model? A clinical epidemiology investigational approach*

One-year funding

Dr. Angela Barbara, Health Information Research Unit, McMaster University, Hamilton

*Living with and managing hemophilia from diagnosis and through key care transitions: The journey for families of children with hemophilia*

First-year funding

Dr. Roberta Woodgate, University of Manitoba, Winnipeg

In 2013 one **CHS—CSL BEHRING—AHCDC HEMOSTASIS FELLOWSHIP IN CONGENITAL AND ACQUIRED BLEEDING DISORDERS RESEARCH** was funded:

*Investigating the contribution of von Willebrand factor (VWF) propeptide mutations to type 3 von Willebrand disease (VWD) using blood outgrowth endothelial cells (BOEC) –*

One-year funding

Mackenzie Bowman, Queen's University, Kingston.

In 2013 two **CHS–BAXTER FELLOWSHIPS FOR NURSES AND ALLIED HEALTH CARE PROVIDERS** were funded:

*An institutional pilot study to investigate exercise patterns in boys with hemophilia*

One-year funding

Vanessa Bouskill, MN, RN(EC), Nurse Practitioner-Pediatrics, and

Pamela Hilliard, BSc (PT), Physiotherapist, Division of Haematology, The Hospital for Sick Children, Toronto

**CHS Research Advisory Committee** – The Research Advisory Committee (RAC) has met three times since January 2013 and accomplished many tasks including fine-tuning research program application guidelines and parameters for the new CHS–Baxter Fellowship Program and the CHS–Novo Nordisk Research Psychosocial Program and finalizing the terms of reference for both the PRC and RAC committees.

**CHS Peer Review Committee (PRC)** – The new Peer Review Committee, under the leadership of Dr. Nancy Dower, completed its grant review process as scheduled in March 2014.

## SAFE, SECURE BLOOD SUPPLY OF CLOTTING THERAPIES

**Safety and supply issues** – The Blood Safety and Supply Committee worked on the following issues over the last year:

- Recommendations on a 5-year donor deferral of MSM (men who have sex with men);
- Communications with Health Canada to end the HIV-O deferral of donors who have lived in or visited certain countries in West and Central Africa;
- Lobbying the provinces and territories to have representation of recipient organizations on the CBS Board of Directors;
- Increased representation on provincial blood advisory committees;
- Project Recovery to make use of FVIII in Canadian donor plasma in collaboration with the WFH, Biotest and Grifols. This project was finalized and an announcement was made at the WFH Global Forum in September;
- The *Clotting Factor Concentrate Utilization Working Group* with AHDCDC, CANHC, CBS, Héma-Québec and others to develop an integrated national information system to replace the current iteration of CHARMS, Helitrax and EZ-Log;
- Communications to membership through *Hemophilia Today* and the Web site about products in the pipeline;
- Communications with Health Canada, CBS, the provinces and territories, and individuals on the issue of plasma collection sites using paid donors;
- In September 2013, CHS received a Lifetime Achievement Award from Canadian Blood Services for its work to promote a safe and secure supply of blood, blood products and their alternatives.

## OUR GLOBAL RESPONSIBILITY

**International Development** – The Quebec Chapter conducted a visit to Nicaragua in April 2013. A CHS-Bangladesh assessment visit took place in March 2013 and an application for approval as a twin submitted to the WFH was accepted in the fall. An action plan was jointly developed by both partners and submitted to the WFH in December. The Quebec Chapter will have a final wrap-up visit to Tunisia in March 2014, thus ending the formal partnership. Hemophilia Ontario submitted a new twinning data questionnaire to the WFH in April and completed an assessment visit in Tanzania in the fall. The Tanzania partnership was confirmed by the WFH and Hemophilia Ontario submitted its action plan in December.

## INCREASED MEMBERSHIP

**Increased Membership** – The National Membership drive was finalized in November 2013. The CHS now has over 2,600 member names in its database and new names are added on a continuous basis. The membership committee will meet in early 2014 to discuss strategies to help our chapters meet the needs of these new members.

## GOVERNANCE

**By-laws** – The CHS is renewing its by-laws to comply with the new Canada Not-for-profit Corporations Act. After consulting with chapters in winter 2014, the Board will recommend revised by-laws to the membership at the June 2014 Annual General Meeting.