## CODE**rouge 2012** I 1st CANADIAN CONFERENCE ON BLEEDING DISORDERS IN WOMEN

C. Cecchini, C. Raymond, D. Franz Currie, D. Page, Canadian Hemophilia Society, Rochelle Winikoff, MD, Ste-Justine Hospital, Montreal, Canada





1st Canadian Conference on Bleeding Disorders in Women

1° Conférence canadienne sur les troubles de la coagulation chez la femme

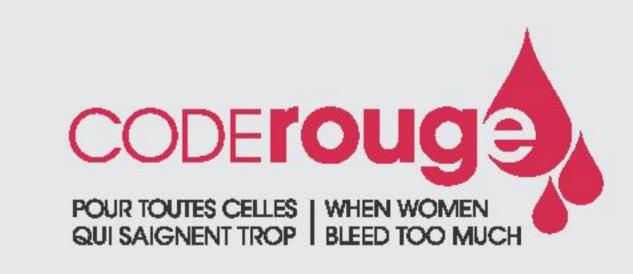
presented by présenté par CSL Behring

ISSUE

Over the past 15 years, the Canadian Hemophilia Society (CHS) has undertaken a variety of strategies to raise awareness about bleeding disorders in women, provide support to diagnosed women and promote access to comprehensive care. As of May 2012, there were 3,226 women with inherited bleeding disorders registered at Canadian hemophilia treatment centres (HTCs) and 6 out of 25 HTCs have established multidisciplinary clinics for women. However, the majority of women with an underlying bleeding disorder remain undiagnosed. In 2011, the CHS Board of Directors identified improving access to care for girls and women with bleeding disorders as a key strategic direction and proposed that CHS bring together its many resources into a clearly branded women and bleeding disorder program.

## METHODOLOGY

1. A multidisciplinary advisory group was established consisting of health care providers and patients who provided input into the development of the program logo, tagline, objectives and outreach strategies.







- 2. On May 25, 2012, in Toronto, coperouge was officially launched at the 1st Canadian Conference on Bleeding Disorders in Women hosted by the CHS.
  - The objectives of the conference were:
  - To increase knowledge about the management of bleeding disorders in women.
  - To increase understanding of the impact on quality of life of women affected by a bleeding disorder.
  - To increase understanding and knowledge about comprehensive multidisciplinary clinics for women with bleeding disorders.
  - To increase knowledge about state-of the-art research related to bleeding disorders in women.

240 participants were part of history by attending the 1st Canadian Conference on Bleeding Disorders in Women.

HEMATOLOGISTS | OBSTETRICIAN/GYNAECOLOGISTS | SOCIAL WORKERS | NURSES | PHYSIOTHERAPISTS

RESEARCHERS | LAB TECHNOLOGISTS | INDUSTRY REPRESENTATIVES | WOMEN AFFECTED BY A BLEEDING DISORDER

3. Each of the ten CHS chapters has identified women affected by a bleeding disorder who have volunteered to become coderouge ambassadors. Their role will be to coordinate, in collaboration with their chapter, provincial coderouge outreach and awareness efforts targeted at women. The coderouge ambassadors were sponsored to attend the May 25 conference and to participate in a training workshop on May 26 that provided them with an opportunity to gain new skills and resources to assist with the implementation of coderouge at the local level.





- **4.** The Society of Obstetricians and Gynaecologists of Canada (SOGC) is collaborating with the CHS to educate and raise awareness of obstetricians, gynaecologists and family physicians about controuge through:
  - exhibits and speakers on the topic of bleeding disorders in women at medical conferences.
  - the revision and promotion of SOGC guidelines on the obstetrical and gynaecological management of women with bleeding disorders.

## **OUTCOMES**

As a result of the coperouge program it is hoped that within four years the number of women registered in comprehensive care clinics will have increased by 50% from 3,000 to 4,500 and that formal programs for women with bleeding disorders will have been established in all 25 Canadian comprehensive care clinics. And most importantly, that girls and women who bleed too much will no longer have to suffer in silence and will have access to appropriate medical care from health care providers with expertise in the diagnosis and management of inherited bleeding disorders.

## www.coderougewomen.ca





