



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

June 2011

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CHARITABLE REGISTRATION/  
ASSOCIATION DE BIENFAISANCE  
11883 3094 RR 0001

**Re:Information regarding HERO: An online study of the impact of hemophilia A & B on patients and families**

Dear Member,

The Canadian Hemophilia Society (CHS) would like to inform you of the HERO (Hemophilia Experiences Results Opportunities) survey and provide you the opportunity to take part if you so choose.

HERO is a study conducted in 12 different countries and will include about 1200 patients and caregivers. The aim of the study is to explore the psychosocial issues in hemophilia A & B and their impact on the various aspects of life, both for patients and their families and partners. The data collected will enhance the understanding of what it is like to live with hemophilia. Ultimately, HERO may inform strategies to improve hemophilia management.

The study findings will be made known to healthcare providers, patients, and patient advocacy organizations through presentations at hemophilia conferences, publications in scientific journals, leaflets and websites.

HERO is being led by the HERO International Advisory Board (IAB) composed of prominent health care professionals and hemophilia patients from around the world. Kantar Health, a research company based in the UK, will be administering the questionnaire and analysing the results on behalf of the HERO IAB and the sponsor. None of the questions posed in the questionnaire are of a marketing nature.

The survey would require approximately 40 minutes of your time. You would be asked personal questions about your family, including hemophilia history and demographic information (race, religion, income, region in which you live, etc.); your/your child's hemophilia; your and your family's feelings about hemophilia; how hemophilia impacts your/your child's life, work and activities (includes questions about sexual life for men with hemophilia); and your/your child's physical and emotional health.

You would not be charged to participate in the survey. You would not be paid for completing the survey. Upon completion of the survey a donation of \$50 would be made to your CHS chapter.

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**Note:** The survey can only accept one respondent per household, therefore only one member of your household can be eligible for the \$50 donation to your CHS chapter.

There is no immediate direct benefit to you/your child associated with your participation. However, we believe that the information obtained will be valuable to the community. There are no significant risks to your participation in this study; however, answering some of the questions could cause you to feel uncomfortable or upset.

**Please note: Personal identities of the survey respondents will be treated with the strictest confidentiality, in accordance with relevant Data Protection laws. You will remain completely anonymous as your answers to survey questions will not be connected to you individually, but rather aggregated and analysed together with the rest of the respondents.**

Participation in this survey is voluntary. You have the right to refuse participation in the study or to withdraw at any time.

If you agree to participate, please click on the link below. Upon entering the website, you will be asked to provide your email address so that you can be sent your own unique link to the survey. Your email address will not be linked to your survey responses.

Canadian English patients' version:

<http://online.tns-global.com/wix/p934338439.aspx?country=4105&l=9>

Canadian English parent version:

<http://online.tns-global.com/wix/p934419923.aspx?country=4105&l=9>

Should you have any questions or complaints about the survey, please contact the project team at [HERO-Canada@kantarealth.com](mailto:HERO-Canada@kantarealth.com).

If you have questions about what it means to be in a research study, you can call Quorum Review (a research ethics board that reviews this study) at 888-776-9115, or visit the Quorum Review website at [www.quorumreview.com](http://www.quorumreview.com).

Best regards,

David Page, National Executive Director, Canadian Hemophilia Society