

SSC Subcommittee Project/Collaborative Project

- Name of the Project: **CONSENSUS DEFINITIONS IN HAEMOPHILIA**
- Person responsible (Chair / Principal Investigator): Dr. Victor Blanchette (Canada)
- Members:
 - Dr. Alok Srivastava (India)
 - Dr. Marijke van den Berg (The Netherlands)
 - Dr. Rolf Ljung (Sweden)
 - Dr. Mike Soucie (USA)
 - Dr. Marilyn Manco-Johnson (USA)
 - Dr. Nigel Key (USA)
 - Dr. Alessandro Gringeri (Italy)
- Aim / Mandate of the project: The mandate of the project will be to review published definitions for primary and secondary prophylaxis, types of bleeds (joint, muscle, significant soft tissue, organ, etc.), target joints and high/low responding inhibitors in the context of long-term factor prophylaxis for persons with haemophilia. The definition of a re-bleed will also be considered. These definitions are critical for standardization of future prospective prophylaxis clinical trial.
- Methodology: the project members will decide if a formal process such as the Delphi method should be used in the development of consensus definitions. This approach has been used by Canadian Investigators but would now be expanded to an International group of health care providers expert in the area of haemophilia care.
- Year of starting: Dec 2009
- Annual report of project: a critical review of relevant information to prepare definitions of primary and secondary prophylaxis, type of bleeds (joint, muscle, etc), response to treatment of an acute bleed, target joint and high/low responding inhibitors in the context of long-term factor replacement therapy in persons with haemophilia has been done. The proposed definitions will be posted on the ISTH website for broad review and comment. Final revisions will then be made to the definitions prior to publication of the recommendations in the Journal of Thrombosis and Hemostasis.
- Year of completion (expected): 2011