

SSC Subcommittee Project/Collaborative Project

- Name of the Project: **CONSENSUS DEFINITIONS IN RARE BLEEDING DISORDERS**
- Person responsible (Chair / Principal Investigator): Dr. Flora Peyvandi (Italy)
- Members: Dr. Donna DiMichele (USA)
Dr. Amy Shapiro (USA)
Dr. Paula Bolton Maggs (UK)
Dr. Christine A. Lee (UK)
Dr. Claude Negrier (France)
Dr. Armando Tripoli (Italy)
Dr. Alok Srivastava (India)
- Aim / Mandate of the project: The mandate of the project will be to propose consensus definitions of the rare bleeding disorders in terms of the factor levels that would define the condition and their severity. Such definitions are critical for standardization of work in clinical trials and for reporting in the literature. No consensus definitions exist at present for these conditions.
- Methodology: The project members will review published literature and data on file in registries of people with the rare bleeding disorders with regard to the clinical profile of their bleeding, correlate them with their reported factor levels and propose definitions of these conditions and a system for grading of their severity.
- Year of starting: Dec 2009
- Annual report of project: Project members made a review of published literature on each single factor deficiency and analysed the experiences obtained by different networks and registries on the clinical profile of patients carrying different factor levels. At the end of this work, a manuscript was prepared to finally propose a consensus clinical and laboratory scale of severities to be published on JTH as SSC communication. However before discussing this proposal at the forthcoming SSC meeting in Kyoto, project members agreed to ask for comments and suggestions by other renewed experts in the field. After having received their comments, members are working to finalise the manuscript incorporating received suggestions.
- Year of completion (expected): 2011