

## **Treatment of rare bleeding disorders in Europe; the French organisation: *J. Goudemand***

Dr. Goudemand reported that patients affected with rare bleeding disorders in France are included in a national project: FranceCoag Network. This is a prospective multicenter national cohort of patients affected with severe and hereditary haemorrhagic disorders. FranceCoag network is funded by the French health Ministry and coordinated by a public health institution: INVS (Institut National de Veille Sanitaire). Beside the epidemiologic objectives, the aim is to set up a surveillance system able to investigate any unexpected events occurring in this population. Inclusion criteria are defect (<30%) in FVIII or IX, severe defects (<10%) in FII, V, VII, X, XI, XIII, afibrinogenemia, severe VWD. At that time 4049 patients registered in 37 French centres have been included in the project and 3439 record forms analyzed. There are 3103 patients (90%) with haemophilia, 239 (7%) with severe VWD and 97 (3%) with other rare bleeding disorders. Clinical and biological data are collected as part of the regular follow up (main bleeding episodes, surgeries, treatments, coagulation tests...) and monitored by the coordinating centre. The project (<http://www.francecoag.org>) is opened to any interested researcher with the agreement of the steering committee. Regarding the treatment, several specific concentrates (VWF, FVII, FXI, FXIII, Fibrinogen, PCC) are available in France to treat these patients.