

FranceCoag Network: a national multicenter prospective cohort for congenital bleeding disorders

Hervé Chambost¹, Céline Garnier², Annie Borel-Derlon³, Jeanne-Yvonne Borg⁴, Albert Faradji⁵, Jenny Goudemand⁶, Yves Gruel⁷, Viviane Guérin⁸, Claude Négrier⁹, Brigitte Pan-Petes¹⁰, Marianne Sigaud¹¹, Natalie Stieltjes¹², Fabienne Volot¹³, Dominique Costagliola¹⁴ and Florence Suzan² for the FranceCoag Network¹⁵

Hemophilia Treatment Centers of ¹Marseille, ³Caen, ⁴Rouen, ⁵Strasbourg, ⁶Lille, ⁷Tours, ⁸Bordeaux, ⁹Lyon, ¹⁰Brest, ¹¹Nantes, ¹²Paris Coc hin, ¹³Dijon; ²Coordinating Center of FranceCoag Network, French Institute for Public Health Surveillance, Saint Maurice, France; ¹⁴Inserm U720 Paris, France ; ¹⁵<http://www.francecoag.org>.

The FranceCoag Network is a prospective national cohort of patients affected with hemophilia and all severe hereditary hemorrhagic diseases except platelet disorders. It was set up in France in January 2003 to replace the previous project dedicated only to hemophilia. It is coordinated by the French Institute for Public Health Surveillance (Institut de Veille Sanitaire) and its steering committee comprises representatives of clinicians, patients, and research and health institutions.

The main objectives dedicated to epidemiology and pharmacosurveillance are : 1/ to assess number and characteristics, including treatment, of patients affected with these severe hemorrhagic disorders and their distribution in France; 2/ to implement a surveillance system able to investigate immediately any suspicion of transmission of new emerging agents related to the treatments. This project includes also a bio bank and is aimed to promote research projects.

Inclusion criteria are: FVIII or IX defect (< 30IU/dl), severe deficiency (<10 IU/dl) in FII, V, VII, X, XI, XIII or FI (< 0.1 g/l) or severe von Willebrand disease (VWD) (BT>15mn or VWF:RCo<10 IU/dl or FVIII:C< 20 IU/dl). Anonymous data including severe bleeding episodes, surgical procedures, replacement therapy and occurrence of inhibitors, are electronically transmitted yearly.

By October 2nd 2007, 5007 patients had been included in 40 participating treatment centers. The diseases are hemophilia A (n=3480; 70%), hemophilia B (n=755; 15%), VWD (n=572; 11%) and allied rare bleeding disorders (n= 200; 4%) distributed as follows : deficiency in factor I (n=26), factor V (n=23), factor V and VIII (n =4), factor VII (n=60), factor X (n=11), factor XI (n=58) and factor XIII (n=18).