

FRANCECOAG NETWORK: A NATIONAL MULTICENTER PROSPECTIVE COHORT FOR SEVERE HEREDITARY HAEMORRHAGIC DISEASES.

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<http://www.francecoag.org>

The FranceCoag Network is a prospective national cohort of patients affected with haemophilia and severe hereditary haemorrhagic diseases except platelet disorders. It has been set up in France since January 2003 as replacement of a previous project only dedicated to haemophilia (Suivi thérapeutique National des Hémophiles). The objectives are to know the exhaustive number, type and characteristics of these patients registered in French specialised haemophilia centres. Inclusion criteria are: FVIII or IX defect (<30%), severe defect (<10%) in FII, V, VII, X, XI, XIII or FI (< 0.1 g/l) or a severe form of VWD defined as BT>15 min and/or FVIII<20% and/or VWF:RCo<10%. Once per year centres send informations on severe bleeding episodes, surgery, replacement therapy *i.e.* type of concentrate, units, place of treatment and main complications (including new inhibitors). These data are collected and monitored by a coordinating centre attached to a public health institution (InVS). Direct transmission of information via a protected web site is under development. The follow-up of the study is ensured by a steering committee (clinicians, coordinators, committed health institutions) periodically extended to scientific experts, other public health agencies and representatives of patients association. On April 2004, 2685 patients were included by 36 centres. The diagnosis established for 2336 of them are: haemophilia: 2086 (89%), severe VWD: 177 (7%), severe defect in other coagulation factor: 73 (3%). The progression is of 200 new patients per month. Beside its epidemiologic interest, this cohort will also promote transversal research projects on this population such as Pups cohort.