

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

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This French prospective national cohort aims to describe the principal characteristics of patients affected with hemophilia and severe hereditary hemorrhagic diseases except platelet disorders from all French hemophiliacs centers.

This cohort has been set up in France since 2003 after a previous project only dedicated to hemophilia started in 1994. Data, collected each year, are monitored and analysed by a coordinating center attached to a public health institution (InVS)-

On september 2005, 4018 patients were included by 37 centers. The diagnosis are hemophilia A (HA) n=2901(72%), hemophilia B (HB) n=605(15%), VWD n=375 (9%), other defects: n= 137 (4%). 389 patients were infected by HIV1, 1480 by HCV, mostly in severe hemophilia (50% of severe HA and 40% of severe HB). Since 1994, 62 deaths were observed, mostly in hemophiliacs (n=60) and related to AIDS or HCV (n=30) or also hemorrhage (n=8). Inhibitor was observed in 453 patients (25% in severe HA, and about 8% in moderate HA and severe HB)- At the last follow-up, majority of severe HA (79%) and HB (59%) received recombinant products.

Prophylactic therapy is mainly administrated in severe hemophilia, and represents 45% of severe HA and 31% of severe HB. But these proportions are 1.3 higher for patients born since 1992.

Beside its epidemiologic interest, this cohort will also promote sanitary surveillance of this population (blood samples preservation) and is at the origin of research projects.