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

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FranceCoag Network, the French prospective cohort of patients with hereditary hemorrhagic diseases except platelet disorders, was set up in 2003 to replace a cohort dedicated to hemophilia only. This project relies on 40 treatment centres. It is coordinated by the French Institute for Public Health Surveillance.

The main objectives are dedicated to epidemiology and pharmacosurveillance, including a biobank. FranceCoag Network promotes also research projects. Inclusion criteria are: FVIII or FIX <30% for hemophilia and (VWF:Ag<30 % or VWF:RCo<30 % or FVIII:C<20 %) for von Willebrand disease (VWD).

By November 2009, 6622 patients had been included, representing a 31587.6 person-year follow-up (median: 3.9 years; extremes: 0.0-15.9). Among 6467 patients alive at last visit:

- the diseases were distributed as follows: hemophilia A (n=4214; 65.2 %), hemophilia B (n=928; 14.3 %), VWD (n=1008; 15.6 %) and other rare bleeding disorders (n=317, 4.9 %, see details in Goudemand’s abstract).
- the repartition of hemophilia A and B is: 37.4 and 34.5% severe, 19.1 and 33.6% moderate, 43.5 and 31.9 % mild, respectively.
- 7.2%, 25.5% and 7.0% of the patients were seropositive for HIV, HCV and for both viruses respectively.

Death, that occurred in 155 cases (median age = 52.2 years), was mainly related to C hepatitis (n=36), AIDS (n=16), haemorrhage not linked to HCV (n=25) and cancer not linked to HIV/HCV (n=24).

The progressive increase of the proportion of mild forms over time, suggests a close exhaustiveness for patients with haemophilia. FranceCoag Network is helpful to improve the epidemiological knowledge in bleeding disorders.