FRANCECOAG NETWORK: A NATIONAL MULTICENTER PROSPECTIVE COHORT FOR CONGENITAL BLEEDING DISORDERS

H. Chamboat1, V Demigue2, P Gautier3, V Gay4, C Négrier5, B Pan-Petesch4, N Trillot4, T Mrossaët6, P Chamouni7, P Stieljes8, A Doncarli9 and F Suzan2 for the FranceCoag Network
(http://www.francecoag.org)

1Hemophilia Centers of 1Marseille, 2Caen, 3Chambéry, 4Lyon, 5Brest, 6Lille, 7Nantes, 8Rouen, 9Cochin
2Coordinating Center of FranceCoag Network, InVS, French Institute for Public Health Surveillance, Saint Maurice; France

FranceCoag Network is the French registry for patients affected with hemophilia or severe form of other hereditary hemorrhagic diseases (HBD) except platelet disorders

Objectives

To get Epidemiological knowledge for the population suffering from HBD
- characteristics and distribution of the patients
- most significant circumstances of treatment (life-threatening bleedings, surgical procedures)
- details of the treatments (type of concentrate, amounts of units, CED, d-DAPV usage, modalities of treatment i.e. ambulatory, prophylaxis, immune tolerance...)

To contribute to the Pharmacovigilance system by providing tools for the urgent investigation of any suspicion of transmission of emerging agent related to the treatments when a test becomes available

To contribute to Research with 2 main topics:
- Inhibitors (risk factors and modalities of treatment) see posters: T. Calvez & al (17P18); R. D'Oiron & al (20P03)
- Prophylaxis (evaluation of feasibility, observance, tolerance and impact of prophylaxis regimen) and more generally to promote any relevant research project in the field of HBD

The FranceCoag Cohort is financed by the French health authorities. It includes the former cohort SNH* (1994-2002) that was dedicated to pharmacovigilance of hemophilia patients only. Suivi National des Hémophiles (T. Calvez & al)

A steering committee conducts the project (clinicians, committed health organizations, reference centers’ coordinators, patients’ representatives, scientific experts)

The coordinating centre (CC), attached to the French Institute for Public Health Surveillance (InVS), is in charge of data management, control of quality and analyzes the current project, that started in January 2003, includes a database and a centralized biobank

A dedicated web site (www.francecoag.org), is available to get information on the protocol, to load specific forms, to transmit anonymous data at regular visits after information of the patient, to get global statistics and also individual data

For more information about the web application, see the specific poster by A. Doncarli & al (10P18)

A Pups Protocol has been designated within the project to pursue specific research purposes for young boys with severe hemophilia

Criteria for inclusion in the FranceCoag Cohort

Hemophilia A or B : FVIII or FIX <30%- Severe von Willebrand disease (VWD) : VWF:Ag<30 % or VWF:RFcoag / VWF:Ag < 0.7 or VWF:CB/VWF:Ag <0.7 or FVIII:C/VWF:Ag <0.5 or positive RIPA test (ristocetin < 0.8mg/ml)

Severe forms of allied rare bleeding disorders (RBD): FII, V, VII, X, XIII (<10%), FIX (<20%) or Fibrinogen (<0.1 g/l)

Results

A 32 024 patient-year cohort with
- 37 centres participating
- 6 670 patients included
- 28 518 visits recorded (mean : 4.3/pt)

13.6 / 100.000 prevalence of hemophilia A in male French metropolitan population by the end of 2008

38 boys born/year with severe HA/HB in [1992; 2008]

Death has been registered in 162 patients* (median age / 52.4 years). The more frequent causes were : hepatitis C (n=38), AIDS (n=16), hemorrhage not linked to HCV (n=27) and cancer not linked to HCV/HCV-CNS (n=15)

*Among them, 36 patients were HIV-HCV

Conclusion

FranceCoag Network is helpful to improve epidemiological knowledge in the field of HBD

The prevalence of 13.6/10<sup>4</sup> as well as the high proportion of non severe forms that reaches 62% in Hemophilia A, suggest a close exhaustion of the cohort

Besides the epidemiological information, FranceCoag Network provides valuable tools for research projects

FranceCoag Network Participants (*Centers appear according to the number of included patients)

Hemophilia Treatment Centers (*Physicians, Members of the Association CARITMA: Héloïse M. Canclini, CHU Liévin; I Goumendam & al
1st coordinates for the project (clinicians, committed health organizations, reference centers’ coordinators, patients’ representatives, scientific experts)

The coordinating center (CC), attached to the French Institute for Public Health Surveillance (InVS), is in charge of data management, control of quality and analyzes the current project, that started in January 2003, includes a database and a centralized biobank

A dedicated web site (www.francecoag.org), is available to get information on the protocol, to load specific forms, to transmit anonymous data at regular visits after information of the patient, to get global statistics and also individual data

For more information about the web application, see the specific poster by A. Doncarli & al (10P18)