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


1Hemophilia Centers of: 1Marseille, 2Caen, 4Rouen, 5Strasbourg, 6Lille, 7Tours, 8Bordeaux, 9Lyon, 10Brest, 11Nantes, 12Paris Cochin, 13Dijon; 14Coordinating Center of FranceCoag Network, InVS, Saint Maurice; 15Inserm U720 Paris ; France

http://www.francecoag.org

FranceCoag Network is a prospective national cohort of patients affected with hemophilia or severe form of other hereditary hemorrhagic diseases except platelet disorders

Objectives

To get Epidemiological knowledge for the population affected by hereditary bleeding disorders (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. amбулatory, prophylaxis, immune tolerance...)

To contribute to the Pharmacosurveillance system by providing tools for the immediate 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)

Prophylaxis (feasibility, observance, tolerance and impact of standardized prophylaxis regimen)

The coordinating committee (CC) is attached to the French Institute for Public Health Surveillance (InVS).

Webfc, the dedicated web site http://www.francecoag.org

- provides information on the protocol
- allows to load specific forms and global statistics
- will authorize identified participants to get safely individual data, in the next version of the database
- For each informed and consenting patient, centers transmit electronically anonymous data at inclusion and at regular follow-up visits. The CC monitors and analyzes data.

A Pups Protocol has been designated within the FranceCoag project, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

Results

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

FranceCoag Network Participants

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)

Criteria for inclusion

Hemophilia A or B : FVIII or FIX <30%

Severe forms of allied rare bleeding disorders:

FII, V, VII X, XIII (<10%), FXI (<20%) or Fibrinogen (<0.1 g/l)

Severe von Willebrand disease defined as:

Type 1 with VWF:Ag <30%* , Type 2 and Type 3 forms

* Criteria that have been extended since January 1, 2008

As of 9th May 2008:

5352 patients have been enrolled,

260 in the Pups sub-cohort

37 centers participate in the project

- 7 to 580 patients included / center

- Median = 140 patients / center

21 587 forms have been registered (inclusion and follow-up visits) representing a Cohort of 23 197 person-years

Japan Coagulation Factor Network, to pursue specific research purposes for boys with severe haemophilia (see specific posters)