

The European Haemophilia Network (EUHANET) Project

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What is the EUHANET project?

The EUHANET project aims to establish a network to deliver projects that will harmonise and improve the care of European citizens with inherited bleeding disorders. The project started on 1st June 2012 and will run for 3 years.

It will be funded by the European Commission via the Executive Agency for Health and consumers (EAHC) (60%) and from Industry (40%).

The main partner is the University of Sheffield.

Associate partners are:

The European Haemophilia Consortium
The European Association for Haemophilia and Allied disorders

University Medical College Utrecht
Ca Granda, Milan

Other partners 84 Haemophilia Centres.

METHODS

The EUHANET project has four areas of work:

- 1. The certification of haemophilia centres.** The designation and facilities offered by haemophilia centres in Europe vary enormously. This project aims to harmonize this. Criteria for centres delivering two levels of haemophilia care will be developed and will go to wide consultation. Once agreed centres will be able to apply for European certification.
- 2. The Haemophilia Central Website.** A website where useful updated information will be set up and the area included are shown in the panel below.
- 3. European Haemophilia Safety Surveillance (EUHASS).** This will continue as before but will be expanded to include acquired haemophilia, acquired VWD and the severe platelet function disorders in the categories to be surveyed. Centres will now be asked to report unexpected poor efficacy in the absence of an inhibitor. When reporting a thrombosis or malignancy, centres will be asked if they are prepared to answer supplementary management questions to establish how the bleeding disorder impacted on the diagnosis and management of the complication
- 4. The Rare Bleeding Disorder Database.** The database will be redesigned so that prospective data will be collected. Initially two severe disorders will be studied in detail; afibrinogenemia and factor XIII deficiency.

Haemophilia Central Website

A haemophiliacentral website will be set up and it will have information on the following areas:

1. Clinical information on all inherited bleeding disorders
2. A database of all European Haemophilia centres
3. Details of all concentrates in use in Europe
4. Details of all active clinical trials in the area of bleeding disorders
5. Details of all quality control schemes in Europe
6. Information about how haemophilia care is delivered in each European country and the regulations and funding of the care
7. Details about how visitors to a country can get care and how much it will cost them depending on their origin
8. A news service with information about bleeding disorders
9. Details of all available guidelines dealing with bleeding disorder patients
10. Links to all the databases containing information about mutations in genes involved in haemostasis
11. Aggregated EUHASS results
12. A service where European Citizens can ask questions
13. The telemedicine HAEMTRACK system will be available for trial

The location of Haemophilia Centres in Europe



Are you interested in taking part ?

This project is open to all haemophilia centres in Europe.

You can choose to take part in the certification, EUHASS or Rare Bleeding Disorder Database (RBDD) components.

Centres outside Europe can participate in the Adverse Event Reporting and RBDD.

For non-European centres the EUHASS equivalent system is called iHASS and the reporting is identical so that data can be aggregated for annual reporting.

For further information and to express interest please contact Dr Mike Makris

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