

EUHANET

EUROPEAN HAEMOPHILIA NETWORK



www.euhanet.org



The EUHANET PROJECT.

EUHANET is a project aimed at establishing a network of haemophilia centres to work together on a number of related projects to improve the care of European citizens with inherited bleeding disorders.

PARTICIPANTS

The project will be directed from Sheffield in the UK by Dr Mike Makris. There are five associated partners: European Haemophilia Consortium (EHC), European Association for Haemophilia and Allied disorders (EAHAD), University Medical College Utrecht, Medical Data Solutions and Services Ltd (MDSAS) and Fondazione IRCCS Ca' Granda in Milan.

In addition 84 centres from 26 countries have already committed to participating and were part of the original funding application.

FUNDING THE PROJECT

Sixty percent of the funding is provided by the European Commission via its Executive Agency for Health and Consumers (EAHC) and the rest will be raised from industry.

PROJECT DURATION

The project started on 1st June 2012 and will continue until 31st May 2015.

AREAS OF WORK

There are four main areas that EUHANET will work on:



1. Assessment and standardisation of the quality of care of haemophilia centres.

There are 420 known haemophilia centres in Europe at locations shown on this map. The size and services offered vary enormously with some centres caring for more than 350 persons with severe haemophilia whilst others care for less than five. The times and extent of available care also vary significantly.

During the first year of the project the criteria defining two levels of haemophilia care will be developed. There will be extensive consultation during this development.

Once the criteria have been developed centres will be able to apply for European Certification of the level of care they provide based on satisfaction of the criteria.



2. Haemophilia Central website (www.haemophiliacentral.org)

The information available from this site will increase during the 3 years of the project. Information will include:

- Clinical information about all inherited bleeding disorders.
- Database of all European Haemophilia Centres.
- Details of all clotting factor concentrates available in Europe.
- Database of all active related clinical trials.
- A news service with information about bleeding disorders.
- A service for affected individuals to ask questions.

Please register at the website for information on updates to the site as they happen in the future.

3. European Haemophilia Safety Surveillance (EUHASS)

The EUHASS project has been running since 2008 and involves 80 centres from 26 European countries caring for almost 30,000 persons with bleeding disorders. Since the start of the project more than 750 events have been prospectively reported.

Within the EUHANET project EUHASS will continue but will now expand to include acquired haemophilia and acquired von Willebrand disease as well as the serious inherited platelet disorders. Information about the management of thrombotic events when they occur will also be collected.



4. The Rare Bleeding Disorders Database

This is a new activity for a project also previously supported by the EAHC. This database has already provided invaluable data on the natural history of the rare bleeding disorders other than haemophilia and von Willebrand disease. This is now part of EUHANET and as a major new development will collect prospective data on afibrinogenemia and factor XIII deficiency. Central specialized coagulation factor and genetic testing as well as external quality control for these disorders will be offered.

Do you wish to take part or want to know more about EUHANET?

The project is open to all European Haemophilia centres. Centres may take part in one or more of the components of the EUHANET project.

If you wish to participate please contact us:

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