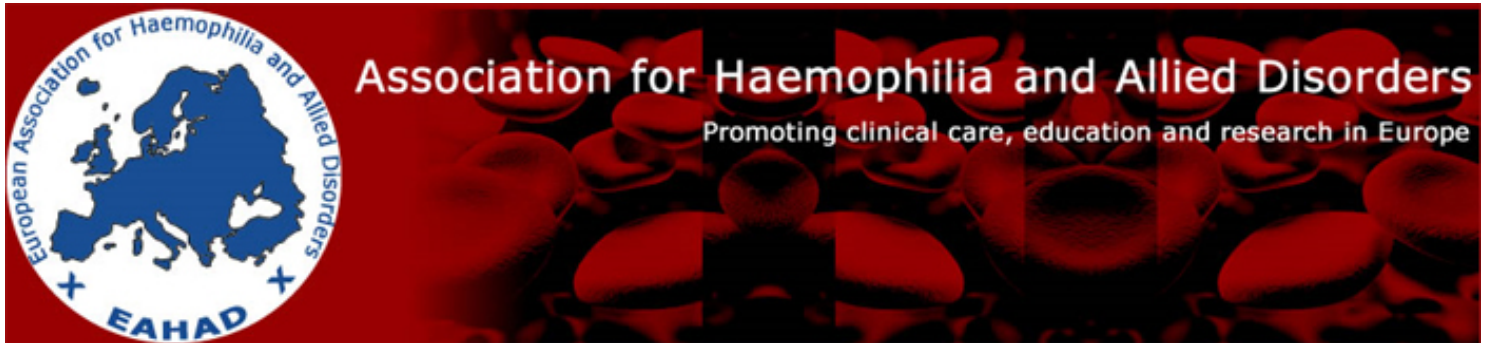


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## EAHAD Winter Newsletter: Issue 1, January 2013

### Welcome from the President of EAHAD

Welcome to the first edition of the Newsletter of the European Association for Haemophilia and Allied Disorders.

The European Association for Haemophilia and Allied Disorders (EAHAD) is a multi-disciplinary association of healthcare professionals who provide care for individuals with haemophilia and other bleeding disorders across the continent. Our purpose is to promote clinical care, education and research that will benefit these patients.



We are very grateful for the support provided since the Association was founded in 2007. In particular, we wish to acknowledge our sponsors for providing unrestricted grants to fund our activities. A number of important achievements have been made by the organization, and the membership as well as participation at the annual congress continues to grow. This is quite encouraging and indicates the importance of an Association based in Europe, but open to people all over the world. During 2012, the primary tasks have been to establish a nurse working party and subcommittee, to direct efforts toward educational activities and to identify ways to support a common database on hereditary bleeding disorders. In addition, EAHAD will continue to support the European Haemophilia Safety Surveillance (EUHASS) as a main partner of the European Haemophilia Network (EUHANET). Apart from EUHASS, EUHANET also conducts several other significant activities with a common goal to secure the quality of care for haemophilia in Europe. This work and further development will continue through 2013. We look forward to several exciting years to come, and depend on your continuous valuable support so that our common objectives can be met.

The aim of this Newsletter is to provide you with updates on the work of the Association as well as developments and current issues within the field of haemophilia.

We hope you enjoy this edition and would like to receive any feedback you may have so we may maximize the usefulness of the Newsletter and our website to provide you with the most timely and valuable information.

See you all and have a safe trip to Warsaw!

Professor Jan Astermark

*EAHAD President*

[Click here](#) for further information about the EAHAD Executive Committee

## The 6th Annual Congress of EAHAD

**6th - 8th February 2013**  
**Warsaw, Poland**

The 6th Annual Congress of the European Association for Haemophilia and Allied Disorders 2013 is to be held in Warsaw, the beautiful capital city of Poland.

For the first time the Congress is organized in the Central-Eastern part of Europe. All lectures are held in the same lecture theatre, so you won't miss any of the sessions due to conflicting parallel sessions.

Don't miss this unique opportunity!

Jerzy Windyga  
*President of the Organizing Committee*



### **Poster Prizes**

We are delighted to announce poster prizes will be awarded as follows:

€1000.00 for first place

€750.00 for second place

€500.00 for third place

[Click here](#) to view the **Preliminary Programme**

You can **Register Now** to attend the Congress, simply [click here](#)

Further information can be found on the Congress website, <http://www.eahad2013.pl/>

## Working Parties

### **EUHANET**

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.

The project will be led 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.

EUHANET is open to all European Haemophilia centres, 84 centres from 26 countries have already committed to participating and were part of the original funding application.

Please [click here](#) for further information and areas of work.

## Working Party to support Clotting Factor Mutation Databases

For many years databases of mutations of individual clotting factors have been an invaluable resource for clinical evaluation of individual patient mutations and for research into structure-function relationships (e.g. Hamsters now [hadb.org.uk](http://hadb.org.uk), or rare bleeding disorders database [rddb.eu](http://rddb.eu)). Historically these databases have been established predominantly in Europe. It has been up to the enthusiastic originator to provide the resource to maintain the ability to receive new reports of mutations as well as to develop their functionality. Most of the existing databases, in addition to details of the individual mutations, also record important patient phenotypic data, e.g. bleeding severity and history of inhibitor. This is an essential feature that distinguishes these databases for ones which are beginning to be established as a result of whole genome sequencing. These will only report frequency of genetic variation, and not whether the variation results in a bleeding state or is merely an asymptomatic polymorphism.

A little while ago EAHAD received requests from several databases for financial support to keep the databases up to date. A Working Party was established to bring together the curators of existing databases to review the best way in which EAHAD could support these databases. To date we have held 6 meetings in which we have considered the spectrum of existing databases, both the active and dormant ones. As well as the technical aspects of the databases, we have reviewed the responsibilities of curators as well as issues related to patient consent and data protection; these latter two issues have become prominent because of recent changes in practice and EU legislation.

Currently each database runs on its own individual bespoke software on a variety of computer servers. We have agreed that so far as possible it would be advantageous if all databases could be converted to a common software system. The Leiden Open Variation Database (LOVD) has been developed with the aid of an EU grant and is a generic database system that can be tailored to the requirements of many different mutation databases. To date 88 different genetic disorders have been established using the LOVD system. Not surprisingly it appears that its functionality will be quite adequate to support the existing clotting factor databases. The decision therefore has been made to start by moving the factor VIII and IX databases to LOVD and to use the experience gained to help with the move of the other databases subsequently. In the next few months, in addition, we are planning to examine in some detail issues related to patient consent and confidentiality in conjunction with representatives of patient organisations. We shall also ensure that our developing arrangements are in keeping with the EU data protection directive which is in the process of being revised.

We would welcome suggestions from interested clinicians and scientists in relation to the databases and the deliberations of the Working Party. These should be addressed to [christopher.ludlam@ed.ac.uk](mailto:christopher.ludlam@ed.ac.uk) (chairman) or Geoffrey Kembal-Cook ([geoffrey@kembal-cook.co.uk](mailto:geoffrey@kembal-cook.co.uk)) secretary.

Other members of the Working Party are Anne Goodeve, Dan Hampshire, Keith Gomez, John McVey, Johannes Oldenburg, Flora Peyvandi, Pavithra Rallapalli, and Stephen Perkins.

## Nurses Committee

The intention of the Nurses Committee is to increase the quality of care by enhancing nursing services as a key component of the comprehensive care team.

The committee aims to establish a symposium led by nurses at the EAHAD Annual Congress. The first symposium is due to take place at the 7th Annual Congress in Brussels 2014.

## Membership

Your membership subscription for 2013 is now due for renewal. If you have not yet renewed your membership for the forthcoming year, please [click here to renew online](#).

Remember to inform the EAHAD Secretariat Office, if you change address so we can update your information.

All membership queries, should be sent to [enquiries@eahad.org](mailto:enquiries@eahad.org)

### Do you know someone who would benefit from EAHAD Membership?

Why not encourage your colleagues to join EAHAD and benefit from the following:

- Reduced registration fee for the Annual Congress
- Network opportunities with peers and specialists in the field
- Six annual issues of our journal, Haemophilia (*Ordinary Members only*)
- Access to [online editions](#) of the Haemophilia Journal (*Ordinary Members only*)
- Have your say at our Annual AGM

For further information about the EAHAD membership categories and details of how to join, please [click here](#).

## Write for the EAHAD Newsletter

EAHAD would be grateful to receive any feedback you have about the Newsletter.

If you would like to submit an article for consideration by the Editor, please send to [enquiries@eahad.org](mailto:enquiries@eahad.org) before **1st May 2013**. All articles of a related subject will be considered.



**It's Your Newsletter - Tell us what you want!**

## Best Wishes from EAHAD

EAHAD would like to wish you the best for the new year and hope to see you at the Congress in February.





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