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4 October 2013

EAHAD Autumn Newsletter: Issue 2, October 2013

Welcome from the President of EAHAD



Dear Member,

A solid platform for the future of EAHAD has been created, and we continually discuss the best ways to further develop and serve the community. There are several options in the pipeline, some of which will start in the coming year. One of them is an educational event to discuss recent publications in the area and how these should be evaluated and interpreted - benefits and weaknesses. The outcome of the discussion among participants and a faculty will be published on the EAHAD website for additional comments by members. The first event of this educational activity will take place in the first half of 2014.

Other important activities in the early phases of planning include a collaboration with the European Hemophilia Consortium (EHC), which is a patient umbrella organization that represents 44 national haemophilia patient organizations from across Europe. For 24 years the EHC has been dedicated to improving the quality of life of people with inherited bleeding disorders. Increasingly influential in the European health policy-making field, the EHC collects and publishes data and quality of life analyses and actively engages with EU policymakers. The aim of this collaboration is to make combined actions to supervise and drive important issues through the EU parliament as well as to initiate activities of mutual interest.

Other important activities in the early phases of planning include a collaboration with the European Hemophilia Consortium. This has the aim of making combined actions to supervise and drive important issues through the EU parliament as well as to initiate activities of mutual interest. We also look forward to following the work of the working party on genetic databases as well as the nurse

working party on genetic databases as well as the nurses subcommittee. We wish to identify ways to support nurses and other health care providers in the hemophilia field in taking an active part in the work on the European level. Comments or proposals for new activities are welcome and will always be carefully considered.

I would also like to take the opportunity to express my sincere gratitude to Professor Jerzy Windyga and Rene Haller and his team at MCI for their tremendous efforts in making the congress in Warsaw such a successful event. Participation was the highest of any EAHAD meeting convened to date, with attendees from several countries inside and outside Europe. The comments and feed-back provided by participants have been carefully considered for the next congress in Brussels on February 26-28, 2014. The one-session format and no exhibitions will be kept, but the meeting will begin on Wednesday afternoon with the first scientific session and end with a late-breaking session on Friday afternoon. There will be four industry symposia over the three days and prior to the meeting there will be an educational event for young physicians and nurses for which pre-registration will be required. We will also make additional space, in terms of time and room, for interactive discussion and poster presentations.

Finally, thank you all for your valuable support and interest in the activities of EAHAD and we look forward to seeing you all soon again.

Wish you all well for the rest of 2013!

Professor Jan Astermark
EAHAD

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

The 7th Annual Congress of EAHAD



26th - 28th February 2014
Brussels, Belgium

The 7th Annual Congress of the European Association for Haemophilia and Allied Disorders 2014 is to be held in Brussels, the beautiful capital city of Belgium.

On behalf of the local Organizing Committee and EAHAD, we have the true honor and the great pleasure to invite you to this very special event which is now a few months ahead.

Do not miss the opportunity to:
Visit the final scientific program now available on the EAHAD

website. The 6 scientific sessions, the late breaking news and four symposia will provide an overview of most recent developments in haemophilia and other bleeding disorders.

Share your research and submit abstract(s) from October 15th.

The best abstracts will be selected for oral presentation or the late breaking news session.

Take part in first edition of the multidisciplinary educational session for physicians, nurses and physiotherapist scheduled on Wednesday 26th Feb. This session will provide a unique opportunity to address in an original format the current challenges of the multidisciplinary care of patients with haemophilia across their life.

Professor Cedric Hermans
President of the Organising Committee

For further information about the Congress, please visit
www.eahad2014.com

EAHAD Working Parties: Update

The EUHANET Project

EAHAD is one of the main partners of the EUHANET project running from 2012-2015. The several stands of the project are progressing well and all the first year deliverables have been completed on time. The following is a brief progress report.

1. The Haemophilia Central website (www.haemophiliacentral.org)

The information on the site is increasing and now has sections on news, guidelines, products, clinical trials etc. All the information is publically available.

2. The Haemophilia Centre locator (www.hclocator.org)

This site is a user friendly enquiry site for the location of European Haemophilia Centres. The site will give the 5 nearest haemophilia centres for any address. Selection of one of the results will give details of the address and telephone details of the haemophilia centre. Details of this website can be given to patients travelling in Europe.

3. The certification of European Haemophilia centres (www.euhanet.org)

The project has developed, after wide consultation, standards for European Haemophilia centres which will be used for grading into European Haemophilia Comprehensive Care Centres and European Haemophilia Centres based on size and range of services offered. From October 2013 all European centres will be able to apply online for certification. All applications will be reviewed by a committee and a certificate will be issued.

4. EUHASS (www.euhass.org)

The EUHASS project is now in its fifth year and continues to expand. The fourth annual report covering the period of 2008-2012 will be available in September 2013 and will give the rates of inhibitors in PUPs and PTPs.

5. The Prospective Rare Bleeding Disorders Database (www.rbdd.org)

This part of the project prospectively follows patients with fibrinogen and factor XIII defects. Patients are registered at entry and then followed six-monthly to investigate morbidity, mortality and treatment.

All the above projects are open for European centres (irrespective of size) to join. Please visit the relevant websites. If you have any questions, comments or suggestions on the EUHANET project please contact Mike Makris
m.makris@sheffield.ac.uk

Working Party to support Databases of mutations in factor VIII and IX genes.

Factor IX database completely revised and now available online

EAHAD members may be aware from a previous report that a Coagulation Factors Mutation Database Working Group was recently established under EAHAD, chaired by Professor Christopher Ludlam, to promote the updating and availability of the various unique European databases of valuable mutation data. Many of these databases have been threatened by lack of funding, availability of appropriate curators or both. The remit of the Working Group is wide, but initial progress has profitably focussed on the two most numerous disorders, haemophilia A and B, starting with haemophilia B (F9) as this database was the most moribund.

The pre-existing F9 database maintained at Kings College London by Dr Peter Green has now been completely updated and expanded, and placed in a new enhanced website administered through Professor Stephen Perkins at University College London (UCL). The URL of the new UCL F9 database is www.factorix.org. In addition, all the data in the revamped F9 database will shortly be mirrored to an LOVD installation in Leiden. Both sites will be freely available to all online users.

The description of the new database and website has recently been published: Rallapalli, P.M., Kemball-Cook, G., Tuddenham, E.G., Gomez, K., & Perkins, S.J. An interactive mutation database for human coagulation

factor IX provides novel insights into the phenotypes and genetics of haemophilia B. *J. Thromb. Haemost.* (2013): 11, 1329-40. Abstract link: PM:23617593.

During the last 18 months a large update of the existing haemophilia A HADB/HAMSTERS site, currently online at www.hadb.org.uk, has also been

undertaken, doubling the total number of mutation reports. work has now begun on the construction of an enhanced haemophilia A (F8) database based at UCL which will eventually replace the HADB site: this site will also be mirrored at LOVD. As for F9, both installations will be freely accessible to all users.

Correspondence is welcomed and should be addressed to Geoffrey
Kemball-Cook
Secretary, EAHAD Working Group on Coagulation Factor Mutation
Databases
geoffrey@kemball-cook.co.uk

Enlargement of the European network of the Rare Bleeding Disorders (EN-RBD) Working Party

The EN-RBD database was established and funded by the DG SANCO, European Community in 2007 to obtain adequate information to address the lacuna in the knowledge of clinical manifestations, treatment and genetic basis of rare bleeding disorders (RBDs). The project originally included 10 European centres with the aim of creating a new, uniform communication tool to insert, manage, review and revise information about patients with RBDs (www.rbdd.eu). The results achieved and the considerable interest that this project has met within our scientific community, make us believe that the project deserved to continue beyond its experimental phase in the interest of the patients. Therefore EAHAD decided to support this project for a three-year period. During 2010, new centres from Germany, Serbia, Belgium and UK in addition to the original 10, have been accepted to join the EN-RBD, in order to increase the number of patients enrolled in the database, optimise data collection and invite some of the new partners to Milan and teach them data entry and the EAHAD support has been used mainly for the IT maintenance of the database.

Read more

Please also find information regarding the initial information for this project by [clicking here](#).

Nurses Committee

In 2012 the working group conducted a survey of nurses working with patients with haemophilia in Europe. Preliminary results were presented in February at the EAHAD Congress in Warsaw. The survey will inform the work for 2013 developing a European Haemophilia Nursing Curriculum. This aims to outline the basic knowledge, expertise and skill required for a nurse

to work in this specialty. The intention is to produce a resource that can be used by nurses in different countries to help in the preparation of educational programmes, to assist in standardising and benchmarking haemophilia nursing care and ultimately to improve the quality of patient care. The document will raise awareness of the role of the nurse in this field and be of interest to other clinicians, educators and those involved in the planning of haemophilia services. The group plans to produce a paper for submission to complement the paper published in Haemophilia in 2009, the

European Curriculum for Thrombosis and Haemostasis. The new Chair of the EAHAD Nurses Working Group is Bert Leenders from Brussels.

Update of the educational working group

The Educational Working Group of EAHAD is delighted to announce the first edition of a multidisciplinary educational session scheduled prior to the opening of the next EAHAD meeting in Brussels. On Wed 26th Feb 2014, between 10AM and 12 Noon, illustrative clinical cases scenarios will be presented and their management interactively discussed by a panel of physicians, nurses and physiotherapist actively involved in adult and paediatric haemophilia. This session should provide a unique opportunity to address in an original format the current challenges of the multidisciplinary care of patients with haemophilia.

Industry Donors



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GRIFOLS

EAHAD would like to thank all companies that have made donations to the Association:

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Membership Renewals

It's almost that time of year

MEMBERSHIP

... cannot wait until next year again for you to renew your membership. In the next few weeks you will be receiving an email with instructions to check your information and pay for your renewal.



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.

Ordinary membership is open to medical practitioners, clinical scientists and members of professions allied to medicine, from any country, who, at the time of application for membership, are working in haemophilia related services and are actively interested in haemophilia and allied disorders. Ordinary members shall be entitled to one vote each.

Associate membership is open to medical practitioners, clinical scientists and members of professions allied to medicine, from any country, who are working in haemophilia related services and who are actively interested in haemophilia and allied disorders, but who are also full time employees in the pharmaceutical industry. Associate members shall not have voting rights.

As a member of EAHAD you will be entitled to the following benefits:

- Updates of activities within the association, including the Annual Conference, working parties and international studies
- Reduced registration fees for the Annual Conference
- Six annual issues of the Journal of Haemophilia (ordinary members only)
- Access to online editions of the Journal of Haemophilia (ordinary members only)
- Access to the members only area of the website, with access to the online membership database
- Notices about other meetings of interest
- Secretariat Services to assist you with any queries
- Association Newsletter

Write for the EAHAD Newsletter

EAHAD would be grateful to receive any feedback or suggestions you have for the Newsletter.

If you would like to submit an article for consideration by the Editor, please send to enquiries@eahad.org. All articles of a related subject will be considered.

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

It's your newsletter - tell us what you want.

Contact Information

If you have any queries about EAHAD or would like to get involved with the Associations activities, please contact the Secretariat Office



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