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5 February 2014

EAHAD Newsletter: Issue 3, February 2014

Welcome from the President of EAHAD

Dear Members,

Another interesting year has ended and we move into 2014 with a great deal of excitement and a number of important challenges to undertake. As part of the continuing evolution of EAHAD, a new educational activity will take place on May 26 in Brussels. A faculty of experts, together with a group of younger hemophilia treaters, will scrutinize a set of recently published papers that have potentially significant influence on the management of patients. Their discussion will cover the pros and cons of the methods, results and conclusions of each paper and how the findings may affect patient care. Hemophilia research is characterized by investigations of relatively small cohorts and evidence-based management based on randomized controlled studies is not easily achieved. Therefore, non-randomized cohort or case-control studies must be evaluated and interpreted as well. The new activity taking place in May will hopefully contribute to this endeavor and also provide an opportunity for members to comment via the EAHAD website. Details of the workshop and how to apply to participate are provided in this newsletter.

We enthusiastically look forward to the Annual Congress in Brussels, now just a few weeks away. Professor Cedric Hermans has made major efforts to host us and the current registration indicates more attendees than any prior meeting. The program promises many interesting sessions. The format and the content of the congress have been highly scored in participant evaluations every year, but, still, some changes have been made based on the feedback provided in Warsaw. We hope these will further increase the value of the event.



Finally, I would like to thank all collaborators, sponsors and cooperative partners for sharing our interest in the field and for supporting EAHAD in its goal to secure optimal care for our patients - I hope to see you all in Brussels.

Professor Jan Astermark
EAHAD

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

AGM 27th February 2014

We would like to encourage you to attend the EAHAD AGM which will take place on Thursday 27th February 2014 at the Annual Conference. There will be two additional items at the meeting which are:

1.EAHAD Executive Committee Election:

The election for new Executive Committee members. There are two candidates for the two positions on the Executive Committee. Ordinary members of EAHAD are entitled to submit a vote. Ordinary members will receive your official voting number by email today the 5th February 2014. If you do not receive this email please contact the administration office (0)44 1355 244 966. To submit your vote online please [click here](#) or [click here](#) to download and return the form.

2. Proposed changes to the constitution:

Please view the proposed resolution to the constitution [click here](#)

Please view the changes to the constitution [click here](#)

Please view the current constitution by [clicking here](#)

EAHAD Educational Workshop 2014

What's new in the area and how to interpret and use this new information?

This educational interactive EAHAD work-shop will critically discuss the latest published literature – trying to identify strengths and weaknesses of each paper and guide health care providers and scientists as to how to appreciate the new information. A faculty of



experts in the field will together with a group of 20 active clinicians at HTCs from varying geographic areas in Europe highlight and scrutinize two recently published papers in each of four different areas. The discussion and outcome of each session will be summarized on the EAHAD website with opportunity for comment by all members of the association.



Location: Sheraton, Brussels Airport

Date: May 26, 2014

Application: A short application including a biography and a letter of recommendation from the Head of Dept should be send to David Massey at the EAHAD secretariat. Interest of 10 minutes presentation of a paper should also be indicated. A maximum of one participant per HTC and two per country will be allowed.

Deadline for application: March 6, 2013

Fee: 200 euros per participant, which will include travel cost and, if required, one night hotel stay.

Agenda

8.30-9.30 Arrivals and Coffee

9.30-10.00 Introduction

10.00-11.30 Session 1 Inhibitors

11.45-13.15 Session 2 Laboratory issues

13.15-13.45 Lunch

13.45-15.15 Session 3 Clinical aspect

15.30-17.00 Session 4 Outcome measures

17.00 Concluding remarks and departures

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.

EAHAD looks forward to welcoming you in Brussels, BELGIUM, for our annual Congress in a few weeks. This 7th meeting will take place on February 26-28, 2014, at the Square Congress Center, located in downtown Brussels, in the vicinity of the world famous Brussels Market Place and historical area.

EAHAD Brussels 2014 Program

EAHAD is pleased to continue to offer an enhanced program with an array high-quality lectures as well as cutting-edge research through the official scientific program and four satellite industry symposia. Specifically, the EAHAD 2014 meeting will offer a program of more than 40 lectures highlighting the latest evidence on inhibitor development, benefits of prophylaxis, global haemophilia care, long-acting concentrates, pharmacokinetics of clotting factors concentrates.

Furthermore, the EAHAD 2014 meeting will for the first time include a 2 hour interactive multidisciplinary educational session that will focus on initiation of prophylaxis in children and management of co-morbidities in older patients.

Many other topics relevant to the haemostasis specialists will be addressed including:

Mild bleeding disorders

Influence of glycosylation on haemostasis

Pathogen reduction treatment for non-fractionated blood products

Modern investigation of platelet functional defects

And much more...

Important Links

For the EAHAD 2014 Program At-A-Glance,

<http://www.eahad2014.com>

For the EAHAD Website, visit <http://www.eahad.org>

To learn more about Brussels, visit <http://visitbrussels.be>

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

The European Commission (EC) has asked member states to support the creation of European Reference Networks for all rare diseases. The EC has supported the European Haemophilia Network (EUHANET) project and one of its aims is to set up a certification scheme for

European Haemophilia Centres. Following extensive literature searches and communication with all European countries, a document of Standards of European Haemophilia Centres was produced. After extensive consultation over several rounds this was modified and the final document was launched at an international meeting in Rome in July and the European Parliament in October 2013.

The standards document which can be found on www.euhanet.org defines two levels of haemophilia centres: European Haemophilia Treatment Centre (EHTC) and European Haemophilia Comprehensive Care Centre (EHCCC). EHCCC will normally care for more than 40 persons with severe haemophilia, offer 24/7 care with high quality coagulation laboratory back up and a full range of facilities. Any centre in Europe can apply for certification and application will be reviewed by a committee that has medical, nursing and patient representation. The application form is available on the EUHANET website. By January 2014, 44 centres have applied for certification.

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.

The most recent update to the current Factor IX database at www.factorix.org and the forthcoming FVIII database includes the installation of a new server in January 2014 with a five-year service. This is the installation of a new server in January 2014 with a five-year service contract that was partly sponsored by EAHAD, together with a new backup server system. The new server now hosts the two web sites, as well as ours for Factor XI (www.factorxi.org). We are most grateful to EAHAD for its sponsorship.

The Factor IX and Factor VIII mutational databases are currently being enhanced by the incorporation of evolutionary data across 47 genomes that range from Fish and Reptiles to Mammals. This will provide most useful information on which residue changes stabilise the two proteins, in contrast to the disease-causing mutations that mostly destabilise them.

Pavithra Rallapalli and Steve Perkins, University College London.

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.

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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 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!

Contact Information

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



Secretariat Office

EAHAD
Northern Networking Events Ltd
Glenfinnan Suite
Braeview House
9/11 Braeview Place
East Kilbride
Glasgow G74 3XH

Telephone: +44 (0)1355 244966

Fax: +44 (0)1355 249959

Email: enquiries@eahad.org



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EAHAD

Northern Networking Events Ltd
Glenfinnan Suite
Braeview House
9/11 Braeview Place
East Kilbride
Glasgow G74 3XH

Telephone: +44 (0)1355 244966

Fax: +44 (0)1355 249959