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11 November 2014

Welcome from the President of EAHAD

Since the last newsletter of **February 2014** many changes have happened. It is especially striking to observe the increasing role that EAHAD plays in Europe for all problems related to the community of persons in charge of patients with congenital bleeding disorders.

As of the 2014 Annual Congress I have taken up the role of EAHAD President until 2016. Cedric Hermans was also named as Vice-President and will become the next President in February 2016. Two executive committee members retired after their three-years term, Jerzy Windyga and Elena Santagostino who have been replaced by our two new EC members Gerry Dolan from UK and Robert Klamroth from Germany.

I would like to warmly thank our newly appointed Past-President Jan Astermark who will remain with us as for two more years and moreover will organize the EAHAD Congress in Malmo in 2016.

I am delighted to inform you all that you can now view the EAHAD EC members and biographies [here](#).

Four more of our colleagues on the Executive Committee will be stepping down and we are therefore looking to replace these members. You will find information on nominations below.

I am very happy to see the revival of the nurse committee and a detailed report on the committee is available within this newsletter. You will see their objectives and composition. We are delighted to announce that the Nurses committee chair Marlies Schrijvers has been invited on to the EAHAD EC.

Cedric Hermans organized a great meeting in Brussels, with an attendance of more than 1,000 delegates (see his report below). As compared with the previous EAHAD Congresses some changes were

made such as for the first time an interactive educational session which was a great success. The Annual congress in Helsinki 2015

which was a great success. The 7 annual congress in Helsinki 2015 chaired by Riitta Lassila looks very promising and we are already very happy with the first statistics given by our MCI, our PCO, which seems to indicate no decrease of registrations.

I can also confirm that the next Congress will be held by Jan Astermark in Malmo in 2016 and by Roseline d'Oiron in Paris in 2017.

You will see below the very interesting reports of four working parties. Although for some of them the work still goes on we would be very happy to receive new applications.

As you will see in Amanda Bok (European Haemophilia Consortium CEO) very comprehensive and clear report, EAHAD and EHC are partnering and working more and more together. We believe this coming closer with EHC will be very beneficial for the whole haemophilia community (patients and caregivers).

In 2014 we have already done some concrete actions such as a) lobbying to ensure that the long acting factor concentrates will be available soon in Europe, b) implementing the certification process of centres and c) giving talks in our annual Conferences.

EHC and EHAD, together also with the WFH, are starting an ambitious project to bring help in some European countries that need support. To face with these multiple tasks and also to support EAHAD own development EHC and EAHAD have opened a joint position for a project consultant.

At the end of this newsletter you will find some information about the Industry donor, the Membership renewals, Write for the EAHAD newsletter as well as the Contact information.

Finally I would like to express my sincere gratitude to all collaborators and partners for supporting EAHAD.

To our members please do not hesitate to share this newsletter with persons who could be interested to secure optimal care for patients with bleeding disorders by becoming EAHAD member.

We hope to see all of you in Helsinki

Professor Philippe de Moerloose
EAHAD President 2014 - 2016

Nurses committee: Paramedics involved in EAHAD: Up and Running, M. Schrijvers

The EAHAD nurses committee would like to increase the involvement of paramedics in the EAHAD, to increase the cooperation between disciplines and to achieve high quality comprehensive care.

Therefore, during next meeting in Helsinki there will be a

multidisciplinary educational session (including active participation through voting) and a lunch session for paramedics. [Read More.....](#)

Please view photos of our nurses committee [here](#).

Executive Committee Nominations

The EAHAD Executive Committee would like to invite you to submit your nominations for new Committee Members. The successfully elected candidates will be announced at the General Assembly on 12th February 2014 in Helsinki, Finland.

If you would like to nominate a candidate for consideration, please complete and return the Nominations Form [here](#). All nominations should be accompanied by the name of the proposer and be seconded by another member. The nominee must also give their consent.

The deadline for all nominations is **12th December 2014**. All nominations should be submitted to the EAHAD Secretariat Office by post, fax or email.

Meetings

EAHAD 2014: Brussels hosted the largest European Congress of Haemophilia, C. Hermans

The 7th Annual Congress was held between 26 and 28 February 2014 in Brussels. More than other diseases, rare diseases such as haemophilia and other inherited bleeding disorders derive enormous benefit from such international scientific meetings.

The conference indeed offered a unique opportunity to share expertise and experience accumulated throughout Europe by doctors, caregivers and researchers actively involved in developing new treatments. [Read More....](#)

Please view the history of attendance records from all previous congresses [here](#).

EAHAD 2015, R. Lassila

Welcome to Helsinki to the 8th Annual meeting of EAHAD2015 in February 11-13.

The City of Helsinki is proud to have you and our community as its guests. Helsinki will offer all participants free access to public transportation. Helsinki offers unique architecture and atmosphere (www.visithelsinki.fi), which we hope you can enjoy in addition to the congress program. On Thursday night the City of Helsinki will serve the participants a buffet dinner at the City Hall, please confirm your participation for the occasion when signing your form of registration to the Congress. We look forward to seeing you in Helsinki!

For further details on poster submission, registration etc please visit the website, www.EAHAD2015.com

Prof Riitta Lassila, President of the Local Organising Committee

Working Groups/Parties

EUHANET, M. Makris

The EUHANET project is now in its third year and is progressing well being on time to produce all the deliverables on time. There are four main areas of work:

- a) Certification of European Haemophilia Centres,
- b) The HaemophiliaCentral.org website,
- c) The prospective rare diseases database
- d) EUHASS.: [Read More.....](#)

Mutation Databases, Ch. Ludlam

The EAHAD Working Party was established to support the preservation and development of databases of variation (mutations and polymorphisms) in clotting factor genes.

Access to the databases, as they are updated and brought on line, is now available via an EAHAD portal (www.EAHAD-DB.org). There are two versions of each database available at this portal. [Read More.....](#)

One-stage and chromogenic FVIII:C, J. Oldenburg

The accurate measurement of FVIII coagulant activity (FVIII:C) in plasma is essential for the diagnosis of HA, defining the severity of the disease and monitoring the concentrate treatment therapy. [Read More....](#)

Risk factor for inhibitor development in PUPs with hemophilia A. A patient-level meta-analysis, A. Iorio, U. Nowak-Gottl

Background: We already conducted and published a systematic review and meta-analysis of observational uncontrolled cohorts of Previously Untreated Patients (PUPs), exploring the possible different effect on the development of inhibitors of pdFVIII and rFVIII Six different Labs were involved in the project, [Read More.....](#)

Industry Support

We would like to express our special thanks to our industry partners who provide financial support to EAHAD in order to develop all our activities. They are as follows:

BAXTER

Bayer

Biotest

CSL Behring

Grifols

NOVO Nordisk

Octapharma

Pfizer

SOBI

EHC-WFH and EAHAD

The European Haemophilia Consortium (EHC) is pleased to be partnering and working closely together with the European Association for Haemophilia and Allied Disorders (EAHAD).

The signing of our Memorandum of Understanding (MOU) last year quickly proved not to be a paper exercise. EAHAD supported the EHC's advocacy campaign to ensure ... [Read More....](#)

2015 Membership



It's that time of year again for you to renew your membership. Within the last 2 weeks you should have received an email with instructions to check your information and pay for your renewal. If you have not received this please contact the administration office.

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 Haemophilia (ordinary members only)
- Access to online editions 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

You should have received your renewal emails last week, if you have not received the email please contact the administration office.

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 Us

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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