

THE GENERAL SECRETARY'S MESSAGE



Dr. Françoise Courtois

2015 has been a very important year. The AGM in Cologne was wonderfully organized by the German HH-Association HVD. New and noteworthy: the active participation of Haemochromatosis International (worldwide HH federation). The scientific sessions have been very informative and generated several collaborative projects. The Lisbon October meeting has been a key date in closing a tight relationship with EHA (EU Hematology Association) to implement a ERN (EU reference Network) for Rare Hematological Diseases: the beginning of an intense and complex "love story"! ■

EFAPH AND RARE DISEASE DAY FEBRUARY 29th, 2015



Düsseldorf, Germany

The 2015 Rare Disease Day was celebrated by scores of merry and colourful demonstrations worldwide. Quite naturally EFAPH took an active part through its 12 European member countries. We cannot go about much detail for each of them but here are 2 representative examples, one in Germany and one in France. ■

See www.eurordis.org/fr/content/rare-disease-day-2016-theme-and-slogan



Orphanet procession in Paris, led by Brigitte Pineau (French HH Federation)



SILVER AWARD 2015 ! A radiant HH patient...

Margaret Mullett, Chair of IHA (Irish Haemochromatosis Association), won the Silver Surfer Award 2015. Under Margaret's 20 year-leadership, IHA has established the equivalent of a multidimensional network using the latest technology to raise awareness of hereditary hemochromatosis. Over 20,000 people have been diagnosed in this country, which has the highest prevalence in the EU. **Congratulations Margaret!** ■



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Calendar 2016

March 2016: Launch of ERN on Rare Haematological Diseases (with EHA)

April 7 - 9 2016: Innsbruck (Austria)
European Iron Club Meeting

April 10 2016: Innsbruck AGM
(EFAPH + HI)

May 26 - 28 2016: Edinburgh
(Scotland) EUCERD Meeting

June 2016: European HH week

June 2016: Patients Empowerment Campaign (EPF) European Parliament, Brussels

MULTI DIMENSIONAL MEETINGS IN COLOGNE, GERMANY, OCTOBER 16-18, 2015



As an introduction to EFAPH and Haemochromatosis International, (HI, formerly IAHA) AGMs, a scientific Conference, open to the public, was dedicated to "Reflections on clinical and practical aspects of HH". International speakers, invited by Dr. Barbara Butzeck attended. Patients groups and experts worldwide are working together to reduce the damage done by haemochromatosis. ■

The European General Meeting (EFAPH'S AGM)

- The statutory activity and financial reports as well as some changes in the Statutes were unanimously approved.
- The Board was renewed (11 members of whom 2 newcomers: Maria Abele, Chair of the Hungary Association and Annick Van Clooster, Treasurer of HVV, Belgium) and the Executive Committee was appointed).
- The projects and activities were reviewed, particularly the opportunity to join one of the European Reference Networks (ERNs) ■



The international annual meeting (HI's AGM)

Haemochromatosis International (HI) is a worldwide alliance aiming at federating HH patients' organisations in 5 continents: North America, South America, Africa, Australia and Europe. Founded in Canada (Biolron 2011, Vancouver), structured in London Biolron 2013 (Rob Evans President - UK), HI is now fully operational (Ben Marris President - Australia). HI and EFAPH joined forces to have both their AGMs in Cologne, taking advantage of the excellent logistics provided by HVD. It has been the opportunity for intense



exchanges between the 2 groups and some EFAPH representatives have been elected as HI trustees: Barbara Butzeck (Germany), Emerencia Teixeira (Portugal), Howard Don (UK), Rob Evans (UK), together with Paulo Santos (Brazil) and Desley White (UK). Besides Ben Marris as President, Rob Evans is past-President, Paulo Santos is Vice-President elect and Desley White is Secretary Treasurer.

HI is very active and will review its progress at the Innsbruck meeting. ■

The scientific session

Sixty attendees (patients, experts, nurses) from 15 countries discussed HH patient's problems and learned something about progress in research. Working groups were set up on several topics. Significantly two large topics stood out orienting the short-term activities:

- **The blood-donation future** has been largely discussed and still is, under EFAPH impulse. Pr. Graça Porto, head of EFAPH's Scientific Committee, insisted on the variety of national/regional practices and on the necessity to promote harmonization. The survey on **blood-donation practices** in Europe, conducted by the Portuguese team, has to be concluded (1,800 HH patients from 12 countries were included) and lobbying from governmental authorities, like in Spain (Cataluña), has to be strongly pursued.

Blood safety is also a major concern for scientists as HH red blood cells might present morphology abnormalities. A working group has been set up to carry out some scientific studies on the matter. The french Blood Establishment partially supports these actions.



- **Arthropathy**, is known to play a major role in the life quality of HH patients. A working group comprising international experts in rheumatology and HH-patients was set up under the leadership of Dr. Barbara Butzeck. Noteworthy are Pr. Pascal Guggenbuhl (France) - working on the efficiency of Anakinra in reducing pains (THERA project) -, Dr. Patrick Kiely (UK) and Dr. Stephanie Finzel. ■



EFAPH has joined Eular since the Cologne meeting.



HI Chairman, Ben Marris and Pr. Pierre Brissot



Ben Marris and EFAPH President, Barbara Butzeck

NEW! EUROPEAN REFERENCE NETWORKS (ERNs) ON THE MOVE!



Pr. Graça Porto,
Scientific Committee
President

Further to the Directive from the European Commission on patients' rights in cross-border healthcare (March 2011), EURORDIS is managing a European project with a view to establishing Rare Diseases (RD) European Reference Networks (ERNs). Two international Conferences (Brussels 2014 and Lisbon 2015) have resulted in defining the frame and objectives of the ERNs. Further, EURORDIS promoted 21 "Groups" to avoid the dispersion

due to the very numerous Rare Diseases. EFAPH volunteered and was co-opted by the Rare Haematological diseases set around a wider patients' advocacy group in the domain of hematological disorders and supported by the European Haematological Association (EHA). The implementation will be based on 5 stages:

- Call for interest from the European Commission for

ERNs (March 2016)

- Submission to the European Commission
- Application reviewed by the European Commission and the Independent assessment Body (IAB)
- Assessments and reports by the IAB, then review by the European Commission
- Final approval by the Board of Member States

Due to EFAPH small size, the integration into the group supported by EHA provides the adequate environment for HH to be covered. EFAPH is represented through its Scientific Committee (Pr. Graça Porto, Pr. Domenico Girelli and Pr. Pierre Brissot). Some national precedents exist within EFAPH and the endorsement of national authorities, including patients organizations and caretakers. This will be done by using a model letter proposed by the group formed around EHA.

As far as EFAPH is concerned, action will be taken to activate its 12-14 national Associations. The whole project will be an intense and quite complex process. ■

HH AWARENESS

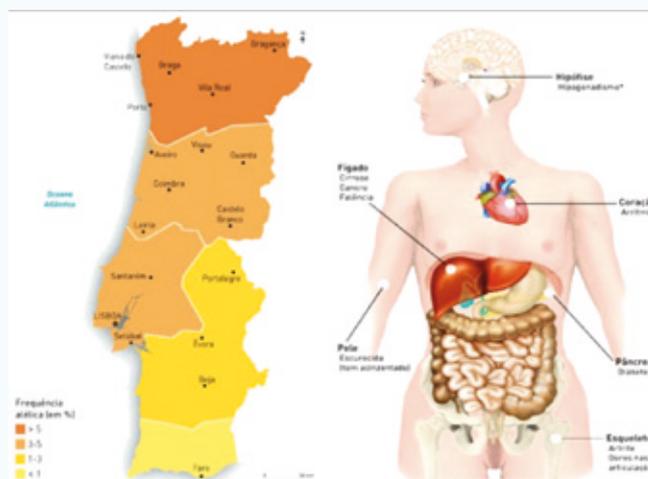
The international rollout of the project to obtain a diagnosis of HH as early as possible is still on. Here are 2 interesting approaches.

PORTUGAL: HH IN TEXTBOOKS!

• 14-15 year-olds will study hereditary haemochromatosis (HH) as an example of genetic diseases over the next few years. A chapter titled "How to study the transmission of hereditary diseases" has been inserted in a science textbook on the Portuguese Haemochromatosis Association initiative. It features some basic information about HH and

also some practical questions about the disease.

• HH has also been presented in a teachers' course in Portugal major cities; none of the 600 attendees met with any difficulties using HH as an example of autosomal recessive diseases. This is an effective and low cost HH awareness strategy, one of EFAPH's major objectives.



FRANCE: INTERREGIONAL ACTION



• Following the Yvelines Pilot project, which targeted 900 GPs (2013/14), a similar campaign was successfully implemented in French Brittany (3,000 GPs, 2014/2015) and is currently underway in the Paris Region. In all, 14,000 GPs will be involved before the end of 2016. Intense lobbying from French and European Patients'

Federations targeting the Paris Regional Health Agency will gradually lead to the setting up of a genuine HH network of Competence Centres and phlebotomy venues (hospitals, French Blood Centres, independent nurses...). This is essential to the implementation of the GPs awareness campaign in this region. ■

A promising contact



A meeting was held in Paris October 2, 2015 between EFAPH representatives and those of La Jolla Pharmaceutical Company (San Diego, California). This company produces synthetic hepcidin and showed great interest in the actions developed by EFAPH.

The Haemochromatosis Society (UK): a new board



Howard Don



David Head



Janet Fernau

Howard Don (President), David Head (Chief Executive) and Janet Fernau (Past President). The Senior Management of the Haemochromatosis Society (HS) has been completely renewed, many thanks expressed to Janet Fernau who devoted many years to the development and notoriety of the HS.

A highly successful concert

A charity concert was organised in Paris on 23rd November 2015 to raise funds for EFAPH, with the internationally renowned pianist Yves Henry and the young violinist virtuoso Hildegarde Fesneau. After a masterclass around a Mazurka of F. Chopin, the 2 concert performers interpreted a Sonata

of W.A.Mozart followed by a “whim” of P. de Sarasate. The concert was splendidly ended by several romantic opuses of F. Chopin interpreted by Yves Henry whose talent, culture and kindness made a conquest of the public.

An exceptional evening!



A new president for HBE Hemokromatózisos Betegek Egyesülete, Hungary.

In 2015, Maria Abelé replaced Pr.Judith Varkonyi, who remains honorary President of the Association. Maria and her team are very active particularly this year in various events to raise the awareness of General Practitioners and of the public at large.



Maria Abele HBE President (Hungary)



Barcelona June 2015 HH awareness day



AEH invited Pr. Pierre Brissot and Dr. Barbara Butzeck to this special event.



A nice cross-border initiative

Norway, Iceland, Denmark, Sweden and Finland are now sharing the same Facebook page.

Nice initiative of inter-nations!



Hildegarde Fesneau and Yves Henry