

HEMO•NEWS

Bulletin N°2 Oct 2013 Barbara BUTZECK (President) + 49 (0)23 24 93 52 34 • info@efaph.eu • www.efaph.eu
Françoise COURTOIS (General Secretary, France) + 33 (0)6 08 25 94 04 • fcourtois.dom@wanadoo.fr

The President's message



Dr Barbara
BUTZECK
(Germany)

Our European network now includes 12 national associations of patients suffering from Haemochromatosis: Germany, Belgium, Denmark (new member), Spain, France, Hungary, Ireland, Italy, Norway, Portugal, the United-Kingdom and Switzerland. During the Vth World Congress on Iron (Biolron in London, 2013), EFAPH efficiently backed the implementation of the new International Alliance of Haemochromatosis Associations (IAHA), which it co-founded (Vancouver, 2011). Three major projects are underway at EFAPH: RAGIODEN (a European Network of Reference Centres), a clinical-epidemiological study on arthropathies linked to Haemochromatosis and the launch of a pilot observatory in France (Yvelines District).

A significant week in London, April 2013 !

The University College of London hosted 3 major events: the Vth World Congress held by the International Biolron Society (IBIS), as well as the General Assemblies of IAHA (International Alliance of Haemochromatosis Associations) and EFAPH (European Federation of Haemochromatosis Associations).

Vth IBIS (Biolron) Congress:

A worldwide event with approximately 500 participants from 35 countries included leading scientists, academics, clinicians and representatives from patient associations, all working on the metabolism of iron.

Three major domains can be highlighted:

- 1 • Genetics: 8 innovative studies on the Diagnosis and Epidemiology of rare forms of non-HFE Genetic Haemochromatosis,
- 2 • New treatments: 3 promising pre-clinical studies on the effect of Hcpidin,
- 3 • Epidemiology:
2 relevant studies :
 - natural history of Haemochromatosis conducted on over one thousand treated type-1 HH patients (Hereditary Haemochromatosis), which has established

a lower mortality rate compared to a 'normal' population,

- the HH penetrance, which identified new genes and allele variants responsible for the clinical expression of the disease.

IAHA (International Alliance of Haemochromatosis Associations) General Assembly: A truly global network

This new alliance was established in 2011 in Vancouver (Canada) and its scope is worldwide. The 5 major continents are represented with Canada, Brazil, Australia, South Africa and Europe (with 12 EFAPH member countries). Highlights: the statutes have now been finalised

and adopted, Pr Robert EVANS (U.K.) has been elected President, Sarah FERNAU (U.K.) designated as Secretary-General and Vice-President Ben MARRIS (Australia) will replace Pr Evans after 2 years. This Alliance aims at federating common activities and promoting worldwide exchanges on research and good practices.



Participants at the 2nd IAHA
General Assembly 1st row,
3rd from the left:
Pr Robert Evans (IAHA President).

EFAPH's (European Federation of Associations of Patients with Haemochromatosis) General Assembly:

The EFAPH played a major role in organising the 19th April, 2013 session (both International and European).

Three major conferences: "HH, the skeleton and the joints" (Pr P. Guggenbuhl), New insights on Haemochromatosis (Pr G.Porto), while Dr Olivier Loreal provided an overview of RAGIODEN, the European Network of Reference Centers (Dr. O. Loreal).

During the EFAPH General Assembly's statutory chapter, the activity

and financial reports were unanimously adopted. Dr Barbara Butzeck was re-elected as President, Dr Françoise Courtois as General Secretary and Dag Erling Stakvik was elected Treasurer to replace Jean-Daniel Kahn who has accepted the role of Adviser to the Board.

2012/2013 Highlights

Denmark becomes EFAPH's 12th national member

The Danish Association's candidacy was officialised during the EFAPH General Assembly in London (April 2013). The Danish Haemochromatosis Association was established in close collaboration with the Norwegian Association, under the aegis of its President, Ketil Toska. The management team includes Dr Nils Milman, who has followed EFAPH's work closely for many years. The number of potential Danish patients is estimated at 20,000. The EFAPH brochure has been translated into Danish and the publishing cost has been offered by EFAPH as a welcome gift.



*Dr Nils MILMAN
Danish Haemochromatosis
Association*

Bloodletting-donations are gaining ground in Ireland

Promoting bloodletting-donations is one of EFAPH's major objectives. The Irish Association has widely influenced the Irish Blood Transfusion

Service (IBTS), which since August 2013 offers on medical prescription four free annual phlebotomies in the Dublin area. This measure will later be rolled out to the entire country.

An example to be followed in our European network.



Three Irish people at the photoshoot for the Awareness Day on June 6th 2013

Very promising connections between France and Ireland

In May 2012, Françoise Courtois developed contacts with the Irish community at a dinner hosted by Mr. Paul Kavanagh (Ireland's Ambassador to France), during a Celtic Event organised by Yannick Le Bourdonnec (YLB Conseil). This offered the opportunity of fruitful exchanges with The Ireland Fund of France and notably with its President, Mrs. Aine Ades, as well as Mr. Patrick O'Connor, former Ireland's Ambassador to Paris. In March 2013, an EFAPH representative attended the concert given by Barry Douglas (Camerata Ireland) at the Embassy of Ireland in Paris.

The Ireland Fund of France granted a €1,500 subvention towards communication on the disease intended for the Irish community living in France. In June 2013, the European Haemochromatosis week was posted on the Embassy's official website.



Mr Paul KAVANAGH, Ireland's Ambassador to France (1st left) and Mrs. Aine ADES, President of the Ireland Fund of France, (2nd right)

EFAPH at the European Haematology Associations' Congress (EHA- Stockholm, June 2013):

Dr Barbara Butzeck (EFAPH's President) and Pr Graça Porto (EFAPH's Scientific Committee President) represented the European Federation in a workshop gathering 11 patients organizations of patients with haematological disorders. The discussions covered the ways to unify the requests from these patients (affected or not by a haemato-oncological disease), as a "unified voice". A topic was highlighted by the Thalassemia International Federation



EHA, Stockholm June, 2013:
Dr Barbara Butzeck (2nd row, 1st left)
and Pr Graça Porto (2nd row, 5th right)

(patients with congenital anaemia due to haemoglobin defects): some solutions has been proposed concerning blood donations from HH patients.

Tackling the Mont-Blanc with the support from the Association Haemochromatosis Ouest (AHO Brittany-France) and from the French Haemochromatosis Federation (FFAMH): or "Sport aids health"! A true feat!

Gisèle Lafond, a young haemochromatotic athlete (who has now been involved in an information-prevention 'crusade' against the disease for several years), planted the AHO/FFAMH flag at the summit of the Mont Blanc on July 1st, 2013. She was accompanied by Marion, a young 21-year-old with diabetes who was on her second ascent. Gisèle Lafond has decided to continue her combat alongside HH patients by supporting the French Federation (FFAMH).



Ascent of the Mont-Blanc: 1st July 2013

Current events

EU Haemochromatosis week

Several events were organised in various countries from May to June 2013, notably in Spain, France, Ireland and Portugal...



HH day in Spain: Dr Mayka Sanchez

News from member countries:

Germany:

HVD stand (Häemochromatose Vereinigung Deutschland) at the Mannheim General Practitioner's Congress (March 2013), HH seminar in Bad Orn (October 2013), participation in the elaboration of new guidelines on bloodletting-donation under the aegis of the Ministry of Health.

Belgium:

Talk given by Tanguy de Decker (HBA) at the Senate to modify legislation in view of bloodletting-donations (May 2013).

France:

Two projects to build the awareness of General Practitioners concerning early diagnosis:

1 • A pilot Observatory project was implemented in the Yvelines (centered around the Hepato-gastroenterology Department of the A.Mignot hospital, Le Chesnay); a "How to deal with" brochure was mailed to 920 GPs (September 2013); the impact of this information campaign will be evaluated in 2014. Extending this experiment to other areas in the Ile de France Region is planned.

2 • A first medical thesis on HH within the Department of General Medicine of Paris VII University has been launched; it is centered around the HH early diagnosis.

Italy:

Financing of two research projects at the University of Milan-Bicocca, including one on Hyperferritinaemia cases showing no signs of iron overload.

Portugal:

Walk in Espinho open to the public at

large (9th June), and organization of a General Practitioners symposium entitled "Iron: too much or too little?" for APH's 10th anniversary. Due to its success, a new session is scheduled for 2014.



Walk in Espinho

Switzerland:

A new HH patients group has been set up in Zurich and Gerda Horn is working towards establishing a Swiss Association.

A major European project (RAGIODEN):

In September 2013, the EFAPH Scientific Committee filed a project with the European Commission for the Rare Genetic Iron Overload Diseases European Network (RAGIODEN). Indeed, the number of European expert

centres is limited and, above all, they are not interconnected. Dr Olivier Loreal (INSERM – Rennes, France) pilots the RAGIODEN (RARE Genetic Iron Overload Diseases European Network) project. Nine national teams are involved with EFAPH's vigorous support ; it is hoped that the EC is expected to respond positively!

A partnership to promote bloodletting-donation in Europe:

Françoise Courtois has reached an agreement with the French Blood Agency (Etablissement Français du Sang-EFS) for 2 renewable conventions, one with the EFAPH and the other with the French Federation

(FFAMH). Their aim is to facilitate all relevant initiatives (documents, events, European lobbying...) to develop bloodletting-donations, not only in France but also in the European network.

Outstanding recent events to the benefit of EFAPH 2012/2013

• 2 golf competitions at Cicé-Blossac (Rennes-France)

The 2nd ProAm Golf and Sailing organised at the Cicé-Blossac Domain in October, 2012. Jean Rialland and Dr Françoise Courtois participated on behalf of EFAPH. It



Jean Rialland (Honorary President of EFAPH) with Dr Françoise Courtois: ProAm 2012

was a real success. The aim of this event was to inform both the participants and the public about the disease and to raise funds; the day finished by a paintings auction sale for EFAPH's benefit.

Further to this success, a 3rd edition took place on October 4th, 2013 and included a fund-raising tombola during the gala dinner. Several major sailors, including the official sponsor of EFAPH, Anne Quéméré, have merrily participated. The tombola winners have been Janny Giorcelli for



ProAm 2013

a sailing week in Majorca and Margaux Rillet for a Mauboussin watch.

Many thanks to Jean-Yves Carré (Cicé-Blossac Domain manager) and to his team, to the professional and amateur players as well as all the donators. This resulted in collecting €2.800. Further to the success a 4th edition is programmed in 2014!

• A highly successful concert:



This concert was organised in Paris on 21st February 2013 by the internationally renowned pianist Anne Queffélec and her son Gaspard Dehaene to raise funds for the EFAPH. An audience of 400 was enchanted with this exceptional evening!

EFAPH is planning to organise another surprise event in 2014!



A meeting important to note:

The next European Congress on the Iron (EIC) In Verona, Italy, from 11 to 14 September 2014; the General Assembly of EFAPH will take place during the Congress