

## MINUTES OF THE 13<sup>TH</sup> ANNUAL GENERAL MEETING Münster (Germany) – June 25<sup>th</sup>, 2017

Edited by : Françoise COURTOIS, Barbara BUTZECK

---

### Agenda: **Appendix 1**

**Presents:** ABELE Maria (Hungary), BAVIN Sonia (Belgium), BUTZECK Barbara (Germany), COUESLANT Béatrice (France), COURTOIS Françoise (France), EVANS Robert (UK), EVANS Patricia (UK), GIRELLI Domenico (Italy), HEAD David (UK), LOREAL Olivier (France), Mc GRATH Ann (Ireland), MILMAN Nils (Denmark), PINEAU Brigitte (France), PORTO Graça (Portugal), SANCHEZ Mayka (Spain), SORRILL Robert (Italy), STAKVIK Dag Erling (Norway), TOSKA Ketil (Norway), TRYGVGE TONNING Nils (Norway), VANCLOOSTER Annick (Belgium), ZOLLER Heinz (Austria).

**Excused:** ALTES Albert (Spain), BRISSOT Pierre (France), BARDOU-JACQUET Edouard (France), DE MAEGHT Stéphane (Belgium), DELWART Bernard (Belgium), DISTANTE Sonia (Norway), DON Howard (UK), HORN SCHLEGEL Gerda (Switzerland), MULLETT Margaret (Ireland), RIALLAND Jean (France), RYAN John (Ireland), TEIXEIRA Emerencia (Portugal).

**Invited:** DEGUELDRE Margot (Germany), GODARD Augustin (France), HENTZE Sabine (Germany), PAWLACK Marta, SMIT Léon, SWINKELS Dorine, UGUZ Fatih, VERBERNE Kim (Netherlands).

---

## Welcome

The 2017 AGM of EFAPH has taken place, like every year, in conjunction with the EIC Congress. Due to the Bioiron occurring in Los Angeles (USA) last May, the EIC scientific sessions (fewer than usually) have been grouped together during one-and-a-half day. The Chair of EFAPH, Barbara Butzeck, opens the meeting by thanking the members to have come so many.

### **1. EFAPH, activity report April 2016 to June 2017 : Dr Françoise Courtois, Général Secretary (Appendix 2)**

Françoise comments the attached diapos, insisting on the highlights since the Innsbruck AGM (April 2016 , 14 months) :

- Strengthening the relationship with Haemochromatosis International (HI), Ketil Toska has been nominated as trustee (Los Angeles AGM, May 2017).
- Strengthening the relationship with EURORDIS, Maria Abele, as new member of the Hungarian Alliance of Rare Diseases, joining Françoise Courtois (Budapest, May 2017, EURORDIS AGM). Additionally, Brigitte Pineau, replacing JD Kahn, has participated in the yearly CEF (Conference of European Federations, Paris, November 2016), noteworthy is the pledge of the European Federations for the new ERNs (ePAGs).
- Thanks to Graça Porto's sustained efforts EFAPH has been accepted in EuroBloodNet. The latter has been recognised by the European Commission (EC) in the Group of non-malignant hematological pathologies.
- Support from EFAPH to the international working group on HH arthropaties (HARI).
- Renewed contacts with the Irish Community in France in order to strengthen the relationship between the two countries about HH (Embassy of Ireland in Paris, September 2016).

- Signature of a cooperation agreement with La Jolla Pharmaceuticals (San Diego, USA) materialized by a grant to EFAPH.
- Continued cooperation with Etablissement Français du Sang (EFS): promotion of the world day of blood donation, cooperation with FFAMH and the Regional Ile-de-France Health Agency to improve the caretaking of HH patients.
- Françoise thanks Pat Evans whose contribution has been essential to produce HemoNews n°5 (attached). Pat confirms that she will continue for the upcoming newsletter in 2018.
- 2017-18 projects :
  - 1° FC, Rob and Pat Evans have promising contacts to set-up a national association in Romania (local workshop towards yearend or 1st half-year 2018?).
  - 2° Improve coordination and synergies between the National Associations on HH awareness ( working group in 2018 ?).
  - 3° Develop «The questionnaire of quality of life» (Pierre Brissot, Graça Porto, and Augustin Godard from La Jolla).

### **The activity report is unanimously approved**

#### **2- EFAPH, financial report (Dag Erling Stadvik, Treasurer – Beatrice Coueslant Assistant treasurer). (Appendix 3)**

The income for the fiscal year 2016 amounts to **€ 30,693.78** . Of which :

-memberships	2,100.00
-grants	28,400.00
-financial income	199.78

The expenses for the fiscal year 2015 amount to **€ 9,654.36**. Of which :

-travel	2,206.90
-AGM Innsbruck	5,096.16
-printing/communication documents, mail	2,124.62
-bank fees	227,28

The revenues exceed the expenses by **€ 21,038.82**. The surplus originates from the first payment on the La Jolla grant.

Dag Erling thanks warmly Béatrice Coueslant for having maintained this year the whole of the accounts.

### **The financial report is unanimously approved.**

#### **3. Election and renewal of the Board and of the Executive Committee 2017/2019)**

The 11 members of the previous Board are candidates for a new mandate :

**Maria Abele, Barbara Butzeck, Françoise Courtois, Dag Erling Stadvik, Robert Evans, Ann Mc Grath, Graça Porto, Mayka Sanchez, Robert Sorrill, Ketil Toska, Annick Van Clooster.**

**All the candidates have been unanimously elected.**

**The Board has 11 members. It designates its Executive Committee :**

President	Barbara Butzeck (Germany)
General Secretary	Françoise Courtois (France)
Treasurer	Dag Erling Stadvik (Norway)
Vice-President	Mayka Sanchez (Spain)
Vice-president	Ketil Toska (Norway)
Assistant-Treasurer	Betty Coueslant (France)

However, Barbara Butzeck (current President) specifies that she has accepted to be candidate again but for the very last time (2 years mandate). She urges a new candidate to make him/herself known rapidly for the next elections (2019).

Pr Pierre Brissot and Mr Jean Rialland are otherwise confirmed as Honorary Vice-Presidents.

Organization chart : **Appendix 5**

#### 4. Highlights of Bioron – Los Angeles, May 2017 (Mayka Sanchez)

Mayka focused her talk on two main topics:

##### 1. Better understanding

- Hemochromatosis and fetus iron stores (E.Nemeth group, LA): Iron transfer to the embryo is dependent on maternal iron status. Maternal iron deficiency resulted in embryo iron deficiency, but maternal and placental iron regulatory mechanisms prevented iron overload of embryos when mothers were iron loaded. Maternal, but not embryonic, hepcidin determined iron transfer across placenta. Appropriate maternal hepcidin levels during pregnancy are essential for fetal iron homeostasis.
- Genetic factor favouring iron excess (Gordon McLaren, USA): The modifier *GNPAT* p.D519G is strongly associated with markedly increased iron stores in p.C282Y homozygotes after correction for age, iron-related variables, and daily alcohol consumption.
- Hemochromatosis and colon cancer (Bojana Ristic, USA): HH increases the susceptibility to colitis and colon cancer in mice. Iron overload disease is a risk factor for colitis and colon cancer. *Discussion: These are experimental findings in mice. There is no proof of higher risk in men.*

##### 2. Better management

- Oral drugs for treating Hemochromatosis: a) Thiazolidonine derivatives may offer novel therapeutics for the treatment of iron overload disorders (HH and thalassemia) by promoting Heparin expression (Jing Liu, China). b) Ginger nanoparticle-derived lipid vector siRNA delivery system targeting intestinal divalent metal-ion transporter 1 (DMT1) as a novel treatment for HH (Xiaoyu Wang, USA). c) Reducing excessive iron absorption by pharmacologically blocking ferroportin with oral Ferroportin Inhibitors provides a novel therapeutic opportunity in hemochromatosis (Naja Nyffenegger, Vifor Pharma Ltd.)
- Should moderate Hemochromatosis be treated? A randomized patient-blinded study of true versus sham reduction of body iron in HFE – HH with moderate Iron overload (Ferritin 300 – 1000ng/l) reveals benefit of treatment by evaluation of fatigue, joint pains, liver toxicity, body toxicity. Therefore Iron removal should be instigated for all hemochromatosis patients whatever the amount of increased body iron stores (*Martin Delatycki, Australia*).

#### 5. EFAPH/Haemochromatosis International (HI) joint meeting - Los Angeles, May 2017 (Rob Evans)

- Rob Evans (past-president of HI) emphasized in his report from the HI-Meeting that it was attended by 30 people: patients, academics, clinicians and scientists from industry. Rob explained the history of HI which was formally established as a UK Charitable Incorporated Organisation in March 2016. Rob summarized the reports of Ben Marris (president) and Desley White (secretary / treasurer) who talked about the developments after the AGM in Innsbruck, April 2016.

- Recruitment of new member organisations: 18 organisations from 15 countries are now financial members of HI and HI is in contact with a further 10 organisations
- The 8 committee members (based in Australia, Brazil, France, Germany, Portugal and the UK) have a Skype “meeting” every month.
- Thanks to grants from Novartis in 2015 and DRG Germany/USA and the help from Bioltron and EIC the face to face meetings at the AGM could be organized. There is a need to seek further sponsorship.
- Election of officers: Ketil Toska (Norway) and Dianne Prince (Australia) were elected as new committee members, Paulo Santos (Vice President/President Elect) was elected as President, Ben Marris stepped down as President and became Past President, Dianne Prince was elected as Vice President/President Elect, Desley White remained as Secretary but Ketil Toska will take over the role of Treasurer, Pierre Brissot, Howard Don, Emerencia Teixeira, Barbara Butzeck and Rob Evans remained as committee members
- Since the AGM 2015 in Cologne the development of International recommendations for the treatment of HFE-Haemochromatosis were set as main objective. Excellent progress had been made on this project, under the supervision of Paulo Santos, Brazil, President. He presented the latest draft version of “**Therapeutic recommendations in HFE Haemochromatosis** “ and went through the text. There was an extensive and valuable discussion from all the people present. A revised version of the recommendations has been produced with a view to submitting it for publication in a scientific journal.

## 6. EFAPH current projects

### 6.1. Status of Eurobloodnet (Pr Graça Porto)

- The meeting in Vilnius (March 9-10, 2017) is a historical date : official launching of the 24 ERNs selected by the European Commission (EC). In total there are 900 medical teams, 310 hospitals in 26 european countries. The iron metabolism disorders are part of EuroBloodNet in the category of non-malignant hematological ailments. There are 66 expert centres in 15 EU countries ; 15 of the 66 are HH centres. After lengthy debates HH type 1(HFE) has been accepted in the Orphanet portal and the HH rare forms do have a different code (ORPHA 220489 and ORPHA 465508) from HFE.
- Being integrated, EuroBloodNet enables the patients to have access to the best care in the EU, promotes good practices and training, develops internet consultations, facilitates clinical trials. But also renders EFAPH and HH more visible, officializing specialized centers.
- It is anticipated, between March and June 2018, to call for new expertise centres.

### 6.2. The HARI group and HH arthropathy:

- Barbara presents the group members (specialists in rheumatology) of the Haemochromatosis Arthropathy Research Initiative – HARI, which was initiated at the EFAPH AGM Cologne 2015 : Dr Axel Braner (Frankfurt, Germany); Dr Graeme Carroll (Freemantle, Australia); Dr Stephanie Finzel (Freiburg, Germany), Prof. Pascal Guggenbuhl (Rennes, France); Dr Patrick Kiely (London, UK); Prof. Henri Menard, (Montreal, Canada); Dr Jochen Zwerina, (Vienna, Austria) and as patient representative Dr Barbara Butzeck, (HVD Germany, EFAPH France).
- The group meets twice a year with the European members; Henri Menard and Graeme Carroll are connected via video-conference.
- Aims of the group are: Raising awareness of the characteristic MCP and ankle features to aid earlier diagnosis and improving QoL of patients with HH-Arthropathy by education and information. In long term a better understanding of pathophysiology, development of special treatment, prevention of severe joint damage and handicap.
- The group focuses on: i) patient advice articles on treatment of HA, osteoporosis and bone health. ii) educational articles for GPs, physiotherapists and other health workers to raise awareness of the discriminatory features of HA (MCP and ankle disease) to prompt diagnostic tests and earlier treatment. iii) projects to characterize the relation between HFE genotype, iron overload and arthropathy.

- The newly designed HARI Logo describes discriminatory features of HA: involvement of Ankle and MCP II and III, as well as Hooks and cysts (imaging).
- As a first result the Patient advice on Treatment of Haemochromatosis Arthropathy was finalized in English in March 2017, translated into German in April, into French in June 2017.
- HARI is proud to get more and more recognition. Patrick Kiely achieved to chair a Workshop on HH-Arthropathy at the next Congress of the *American College of Rheumatology ACR, San Diego Nov. 2017*.

### 6.3 . Quality of life : a questionnaire for HH patients (A. Godard La Jolla et Pr Graça Porto) :

Under advice of Pr Pierre Brissot a questionnaire on Quality of Life QoL was drafted including questions to pain, fatigue and problems with venesection. The survey is almost ready for use, license has to be asked for the WOMAC part.

### 6.4 Awareness campaigns

#### 6.4.1 The Irish experience

In the absence of Margaret Mullet, Ann Mc-Grath reports of awareness campaigns in Ireland :

- a) A photoshoot with the Minister of Health and two famous sportsmen on May 24<sup>th</sup> 2017 to launch the awareness Day on June 1<sup>st</sup>. There were stands in over 30 centres nationwide, manned by volunteers. The Awareness Day generated a lot of attention including articles/photos in National papers and Medical journals, Radio and TV interviews.
- b) On June 5<sup>th</sup> 2017, fourteen ladies of the extended Murray family did the Mini Marathon for the Irish Haemochromatosis Association in memory of their beloved husband, brother and brother-in-law Des who died one year ago as a result of complications from Haemochromatosis. They raised the incredible sum of € 2000. Three other projects were explained like a private Coffee morning on March 8<sup>th</sup> 2017 (raising 2500 €), Raffle for Easter Egg at Kildare Place School (€ 350) and the donation of Boyle Sports (€500).

#### 6.4.2 The French experience : A national awareness week: DETECT/FER

Brigitte Pineau, FFAMH president, gave a presentation on **DETECT /FER**, a national awareness Week targeted at health professionals, in June 2017.

Learning from an EFAPH/FFAMH pilot awareness project targeting 920 GPs, in the outskirts of Paris, in 2013, from the setting up of Haemochromatosis care pathways in the Parisian area in 2016, that allowed the launching of an awareness campaign targeting 11 000 GPs and specialist doctors involved in the diagnosis of HH, in January 2017. FFAMH hunted for the support of key influencers in the health sector before embarking on a large-scope project in June 2017. Teaming up with the biologists' unions, the physicians' unions, the specialist doctors' unions and scientific Societies, they adapted the practical document used in the January campaign. Their endorsers posted it on their websites and newsletters. A video clip, shot for the event, was broadcast in doctors' waiting rooms, for three weeks in June, and a poster, sent by the 3 biologists' unions to their members, was put up in every laboratory. The educational document was handed out to doctors' along with every biological test showing an increase in transferrin saturation. The impact of that campaign will be assessed before next year awareness week. That action benefited every player.

F.Courtois suggested a possible EU coordination for future awareness campaign.

#### 6.4.3 The UK experience in Birmingham

David Head, CEO of the Haemochromatosis Society UK, reported from the Conference for Healthcare Professionals March 31 and for Patients April 1<sup>st</sup>, 2017 in Birmingham, UK under the title « New Understanding of Genetic Haemochromatosis ». David discussed the challenges (New Project, Finance, Attracting an Audience, Defining Key Messages) for the HH society UK as organizer. Finally the event was very successful, due to very eminent international speakers, central location Birmingham,

Audience 100. As the feedback was excellent specially regarding that most presentations were available on video the Society board is thinking of plans for next year.

## 7. Status report on EPF (European Patient Forum): Annick Vanclooster

Annick Vanclooster, who recently accepted to represent EFAPH at the EPF, reported from the latest meetings under the vision: access to high quality, patient-centred equitable health and social care .

- a) 4 thematic areas: Patient Empowerment, Sustainability of patient organisations, Access and Inequalities, Governance.
- b) 5 areas of action: Providing access to quality of care, committing to sustainable investment in health, encouraging affordability of healthcare products and services, implementing access to an holistic range of health and social services, ending discrimination and stigma patients facing in healthcare.
- c) Annick ends with the few on the upcoming campaign for Universal Health coverage for all: #Access 2030... as a main-term objective of EPF making universal access a reality for EU patients by 2030.

Dr Barbara Butzeck closes the meeting and thanks all participants for their committment and participation.

1. February 2018 : EIC 8 – 10th + AGM EFAPH Sunday 11th. (Zurich, Switzerland)
2. May 2019: Bioiron Heidelberg (Germany) – EFAPH + HI AGMs
3. 2020 or 2022 EIC Barcelona? (suggestion from Dr Mayka Sanchez)

### Annexes:

1. Agenda
2. EFAPH Annual Activity report 2015-2016
3. EFAPH Financial report
4. Hemo News EU n°5
5. New organization chart



**Barbara BUTZECK**  
(EFAPH Présidente)



**Françoise COURTOIS**  
(EFAPH Secrétaire Générale)

