

**MINUTES OF THE SIXTH ANNUAL GENERAL ASSEMBLY  
Nijmegen – September 18<sup>th</sup> 2010**

Report : Françoise COURTOIS, Barbara BUTZECK, Jean-Daniel KAHN : December 5th 2010

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**In Attendance:** ALTES Albert (Spain), BRISSOT Pierre (France), BUTZECK Barbara (Germany), COSTA Monica (Portugal), COURTOIS Françoise (France), KUN Levante (Hungary), MULLETT Margaret (Ireland), PINEAU Brigitte (France), PORTO Graça (Portugal), RIALLAND Jean (France), SANCHEZ Mayka (Spain), TOSKA Ketil (Norway).

**Apologies :** BALAGAYRIE Jean-Louis (France), COSTA Joao Manuel (Portugal), KAHN Jean-Daniel (France), MULLANEY Frances (Ireland), STUART MacDonal (UK), BOSTEELS Marina (Belgium), VARKONYI Judith (Hungary).

**Invited :** FINDT Sue (Germany), IMMONEN Kaisa (EPF, Brussels), LUSCIETTI Sara (Spain), SWINKELS Dorine (Netherlands), ZOLLER Heinz (Austria).

**Guests :** EMERY Laura (Switzerland), SCHWEIGER Christian (Switzerland)

Appendix 1

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Welcome to all participants and opening by the President Barbara Butzeck.

Warm thanks to Dorine Swinkels for the excellent organization in the historic heart of the Radboud University Nijmegen.

The resignation of Dr Jean-Louis Balagayrie (President of the French Association- FFAMH) due to health reasons is accepted with regrets. Welcome to Brigitte Pineau, FFAMH General Secretary who represents him and to Levante Kun, representing HBE, instead of Judit Varkonyi. Regretfully noted the absence of Manuel Costa and Brenda Flannery due to unexpected incident.

**I. ACTIVITY REPORT 2009/2010 (BARBARA BUTZECK, PRESIDENT):****1. Report covering the period June 2009 – September 2010 :**

- The Executive Board has met 4 times : September 2009 (Croissy S/S), January 2010 (Frankfurt), June and September 2010 (Croissy S/S). The main decisions have been:
  - Transfer of the official head office from Rennes to Croissy S/S for practical purposes.
  - Consequently update of the statutes (Frankfurt, January 10,2010)
  - Cooptation of Jean-Daniel Kahn to assist Françoise Courtois. Evaluation of the possibility to transfer the bank accounts from Rennes to Norway, then from Rennes to the Paris area. Selection of HSBC Asso Direct (Paris) and transfer of the accounts (see Financial Report). Decision to retain Sophie Segaud, part time accounting and secretarial service.

- With a view to reduce costs, decision to limit the frequency of the meetings by giving priority to those financed externally and to concentrate the Executive Board meetings on 2-3 days.
  - Proposal to the AGM to reorganize geographical responsibilities and to nominate 2 vice-presidents.
  - Preparation of the Nijmegen AGM.
- The most significant actions have been :
- Reactivation of the Haemochromatosis Belgium Association (HBA) with the active support of Françoise Courtois
  - Preliminary contacts in Greece (F.Courtois) and in Denmark (Ketil Toska) with a view to creating new associations short-term
  - Consolidation of the relationship with Dr K. Radziwill, presiding the Standing Committee of the European Medical Doctors (CPME) in March 2010.
  - Active participation of F. Courtois to different meetings of EURORDIS and EPF resulting in the Value + Text Book (Göteborg, December 2009).
  - Finalization of the EFAPH information leaflets (english, german, hungarian and french languages) and preliminary versions in spanish and portuguese languages.
  - Development (François Courtois and Jacqueline Lassale) of the draft of the Sponsorship File, handed to the participants.
  - Feasibility study of a HH Day at the European Parliament in 2011
  - Exploration of the possibility to launch national HH days based on existing experiences in some countries in 2010 (reporting at the AGM).
  - Proposal to create the Scientific Committee of EFAPH.
2. Following the report of the President, some points and particular projects have been discussed :
- Allocation of responsibilities for increased efficiency and EFAPH's expansion :
    - Ketil Toska, in charge of Scandinavian countries,
    - Judith Varkonyi, in charge of Eastern Europe countries,
    - Françoise Courtois, in charge of Latin countries,
    - Barbara Butzeck, in charge of Central Europe countries.
  - European HH Day:

This is the main project for year 2011. It will be presented further in detail by Françoise Courtois. See below (item VI).
  - Sponsorship File : the draft (handed to each participant) will be addressed by email by F. Courtois to all member associations of EFAPH for proof reading and validation. A return is requested at their earliest convenience. The sponsorship file is meant for extended communication about EFAPH,

including funds raising and general visibility. A considerable amount of work has been invested in the document (in english), which will be available before year-end to all member associations.

- The EFAPH leaflet will be translated in Spanish by Mayka Sanchez. For economical reasons it will be printed at the same time as the Portuguese version. The same will be applied probably to Czechoslovakia, Denmark, Italy and Greece.
- The Executive Board's reports: for improved communication all the reports of the Executive Board will be regularly addressed to the Presidents of EFAPH's member associations.

The President's activity report was **unanimously approved by vote**.

## II. FINANCIAL REPORT (KETIL TOSKA, TREASURER) :

### 1- Accounting and banking :

Until now EFAPH's accounting year covered the period from one AGM to the following (for example september to august). The Executive Board (09/03/10) recommends to adopt the calendar year (01/01 to 12/31). Exceptionally the 2010 statements will comprise 15 months.

Historically EFAPH has been formed in France and located in Rennes, where it has its bank accounts. The Head Office has been transferred to the Paris area. The Executive Board has decided to open an account at HSBC Asso Direct in Paris, which is a branch specialized in direct banking for associations.

- 2- For the period 10/01/09 – 12/31/10 (15 months) the total income amounts to 12,635.89 € and the total expenses amount to 15,252.88. But the treasury forecast for year-end 2010 shows a surplus of approximately 7,000 €.
- 3- The overall income and expenses evolution between 2006 and 2010 shows a small but continuous decrease of the cash balance. This is due to the expenses occurred for the formation and expansion of EFAPH. The Executive Board recommended a costs reduction program: less trips and reduction of hotel expenses. **It is also vital to pursue actively the search for new sources of funding**: this is extremely time consuming.
- 4- 2011 Budget :  
EFAPH is reaching a critical momentum in its development and the year 2011 will be decisive. On the expenses side the highlights are the renovation of the website and the HH Day; on the income side sponsors have to be found or confirmed (current contacts, positive and promising, are actively pursued).
- 5- Some points have been further discussed :
  - The model for membership fees is changed as follows: for the small associations (<100 members): 30 €, for the large associations: 200 €.
  - The Head Office will use the part time accounting/secretarial services of Sophie Segaud for a 1,000 € yearly fee.

- 6- Ketil Toska explains that he does not wish to retain the Treasurer charge because of difficulties with french accounting/banking rules and language. This entails to designate a new treasurer.

The Financial report has been **unanimously approved by vote.**

### **III. PRESENTATION OF NEW MEMBERS :**

- **Jean-Daniel KAHN** (French): A retired Systems Director of L'Oréal, he joined recently EFAPH as a volunteer to assist the President and the General Secretary. He has an extented international experience and is both an european and humanrights activist.
- **The new Belgian Association (HBA)** : formed in March 2010 with the support of Françoise Courtois who summarised their brief history, the composition of the Executive Board, the projects.
- **A new group of Danish HH patients** : thanks to the support of Ketil Toska and of the Norwegian Association (NHF), a Danish Association is near to be created.

### **IV. RENEWAL OF THE ADMINISTRATIVE COUNCIL AND OF THE EXECUTIVE BOARD :**

Appendix 5

1. The statutory partial renewal of the Administrative Council taking place every two years, no vote was required on this point. Due to Jean-Louis Balagayrie resignation, his replacement by **Jean-Daniel Kahn** was proposed and **unanimously approved.**

2. **Composition of the new Executive Board** : Appendix 5

The Administrative Council hold its meeting. Taking into account the unavaibility of Frances Mullaney and the new allocation of responsibilities, the Executive Board will be composed of:

President : Barbara BUTZECK

Vice President : Judith VARKONYI

Vice President : Ketil TOSKA

General Secretary : Françoise COURTOIS

Treasurer : Jean-Daniel KAHN

The allocation of responsibilities previously discussed has been confirmed :

Barbara Butzeck, in charge of Central Europe countries,

Ketil Toska, in charge of Scandinavian countries,

Judith Varkonyi, in charge of Eastern Europe countries,

Françoise Courtois, in charge of Latin countries.

**Unanimously voted and subsenquently approved by the General Assembly.**

## V. EPF - A STRONG PATIENTS' VOICE THAT IS HEARD IN BRUSSELS AND THROUGHOUT THE EU :

Kaisa Immonen, EPF (European Patient Forum) Policy Officer presented the objectives and missions of this « umbrella » organization which comprises 44 members (including EFAPH) representing appr. 150 millions of patients in Europe.

EPF is very active at the European level, including the EU authorities, and seeks to make the voice of patients heard. The Value + Policy Recommendations are an important landmark, developed in 2009 in cooperation with EPF's members (including EFAPH) and results in 13 recommendations for more patients involvement in European Health programmes and policy.

EPF's help in building-up EFAPH has been appreciated and the strong link between the 2 organizations is of mutual benefit.

The participation of all EFAPH members to EPF's initiatives is encouraged but should be coordinated with EFAPH's Executive Board. For further informations : website [www.eu-patient.eu](http://www.eu-patient.eu)

## VI. THE NATIONAL HH DAYS (5 EFAPH EXPERIENCES) AND THE EUROPEAN HH DAY'S PROJECT :

Further to the initiative at the 2009 Porto AGM the following countries carried out experiences in national HH Days to verify the feasibility of the concept at both national and european levels.

### 1. The national HH Days

- The Irish HH Awareness Day (first ever, June 3, 2010) has been a great success. Margaret Mullet (IHA President) explained that approximately 150 people herpe in 25 stands located in shopping malls and hospitals throughout the country. Brochures and Information leaflets were distributed. The IHA hopes to extend the number of venues next year. To coincide with the Awareness Day, an information evening was arranged for June 3rd in Monaghan, attended by 200 people. Margaret M. presented the last IHA Newsletter which illustrates the HH Day and other events of this active association. during the last years were briefly presented . See: [www.haemochromatosis-ir.com](http://www.haemochromatosis-ir.com)
- The German HH Awareness Day (first ever, June 5, 2010) in Cologne has been presented by Barbara Butzeck and was attended by 150 people with presentations by medical specialists, a live demonstration of phlebotomy and a practical investigation of the liver by fibroscan for 60 patients and family members. Furthermore 200 persons (general public) were interviewed : 98% have never heard about HH or iron overload diseases.
- The National HH Day Portugal (first ever, June 7,2010) declared by the Health Ministry has been presented by Graça Porto, based on the

report of Manuel Joao Costa. Additionally there were Awareness actions in 5 regions. Members of the portuguese association, wearing special APH caps, participated in the national initiative of hiking and jogging as active sportsmen or as distributors of information leaflets on the way in many cities. A scientific conference was organized by APH in Porto with Maria de Sousa MD,Ph.

- The French HH Day experience (7th event, June 12 ,2010) presented by Brigitte Pineau. In 37 cities HH informations events were organized in health-focused venues as well as in cultural centres with the support of medical experts, FFAMH and AHF members and sponsors. A remarkable awareness was promoted by different media (TV, radio, national newspapers and online newsmagazines. The main messages : « Save your life and that of your family » and « Get your iron overload measured » were delivered.
- The Spanish experiences in 2010 : were presented by Mayka Sanchez based on the report of Alberto Altes. The AEH participated in the celebration of the International Day on Rare Diseases in Barcelona. Furthermore they raised awareness for HH by the Catalan TV marathon for rare Diseases where AEH had an information booth. During the year, 3 informative bulletins were distributed and withthe collaboration with Novartis, a multidisciplinary Spanish/Portuguese scientific group about iron was created. With these experiences, AEH has a good starting point in view of the future spanish HH Day.

## 2. The European HH Day's (EFAPH project) : Appendix 6

The presentation by Françoise Courtois highlighted that improving the awareness of the HH disease as widely as possible (general public, medical professions, authorities) is a major mission for EFAPH, as well as a challenge. It is indispensable to obtain the Parliamentary support both at European and national levels. The idea is to organize a « Public Hearing » at the EU Parliament and preliminary contacts are underway. This implies Parliamentary and financial support, as well as a large communication effort. The latter will materialize in a communication plan to be developed, possibly with the support of a communication agency.

The discussion highlighted the interest and the potential to build on the national HH Days experiences. The scope of the project is very ambitious but the attendants agreed to follow-up on the contacts taken by F.Courtois (particularly MEP Corinne Lepage, Vice President of the ENVI Commission) without delaying it to 2012. Seven following associations declared to organize a national HH Day in June 2011 (France, Germany, Hungary, Ireland, Norway, Portugal, Spain). One of the main difficulties will be to secure the founding.

## **VII. SCIENTIFIC TOPICS AND RELATIONSHIPS WITH PATIENTS ASSOCIATIONS:**

1. Clinical Practical Guidelines for HH: **Heinz Zoller** MD-Ph presented in the name of the EASL Group the 4 topics of the Guidelines which are the results of reviewing 6 000 articles highlighting the variability of the prevalence in the European countries, the penetrance, the diagnostic strategy and the treatment management. Find the short summary in Appendix 7 and the original text on [www.easl.eu/clinical-practice-guideline](http://www.easl.eu/clinical-practice-guideline), published in the Journal of Hepatology **2010** vol.53 : 3-22. Heinz Zoller thanked the HH-Patients Associations for their input and invited them to keep on doing since guidelines are constantly in progress. One major issue of the discussion was how to deal with hyperferritinemia. Furthermore, the audience asked for a simplified summary adapted to the knowledge of HH patients' associations to be translated in their own languages; this demand should be managed by the Scientific Committee (see below).

2. Implication of patients' organization in research: **Pierre Brissot** (MD-Ph) pointed out that patients' organizations are valuable partners in research by identifying the gaps, highlighting the needs and providing financial and logistic support as well as establishing bridges between patients and researchers. He illustrated different experiences on European and French levels. P. Brissot requested EFAPH to develop its involvement in the research of genetic iron overload disorders and underlines the necessity to create a Scientific Committee associating scientists, MDs and patients.

3. Constitution of a Scientific Committee: Further to the suggestion of Françoise Courtois, a Scientific Committee for EFAPH has been constituted:

Graca Porto, MD-PH, IBMC Porto, Portugal (Chair)  
Pierre Brissot, MD-Ph, Pontchaillou University Hospital Rennes,

France

Heinz Zoller, MD-Ph, Medical University of Innsbruck, Austria  
Mayka Sanchez, MD, IMPPC Barcelona, Spain  
John Ryan, MD, Mater Misericordiae University Hospital

Dublin, Ireland

The following aims were established:

- Update and filter information about research results, and provide HH-Patients with valuable and understandable information
- Inform and educate medical doctors on this subject
- Improve the situation of HH-Patients (by considering their specific problems)

The agreed subjects of prior interest are: a simplified summary of the guidelines and a hyperferritinemia algorithm accessible by the associations' members, the use of blood for transfusion and a selection of scientific articles most useful for general practitioners and patients.

A Europe-wide patient registry was discussed. In most European countries (except Scandinavia) data protection of health information concerning private persons is a problem. Usually patient consent is

required to collect data. Finally there was no agreement on building a patient registry.

4. 2<sup>nd</sup> Survey 2010 on HH-treatment (EFAPH questionnaire): **Françoise Courtois (MD)**, Appendix 8.

The aims of this study (similar to that of 2007), were to highlight some topics to discuss and to make consensual proposals. The inquiry was buckled in 4 months (May to August 2010); 8 out of 12 Member countries answered (covering from 25% to 100% of each country). The main results of the survey are:

- The locations for the treatment : rather mixed even very heterogeneous in several countries ;
- A consultation before phlebotomy is carried out by a nurse or by a medical practioner (or both), with a variable frequency and a biological test before phlebotomy is organized in 7 countries but varying widely from one country to another -> a future EFAPH investigation
- The usual cost for phlebotomy is also variable : free in 4 countries, very low cost, up to 750€;
- The cell apheresis is a technique still very little used;
- The volume of blood removed is still not quantified in Spain but is rather well adapted by the other countries ;
- Concerning the use of blood from HH patients for transfusion, 2 countries established national rules (France,Germany), 3 countries began in few places and 3 countries would probably consider it as a national issue... This subject is of a major interest in most countries : 3 countries are ready to be part in a EFAPH's working group (Portugal, Hungary, Norway). The Scientific Committee engaged itself to work on this topic.

### **Conclusion**

The participants expressed their satisfaction with this fructuous meeting regarding the progress in the administrative structures and the EFAPH network, the realizations of different projects as the new leaflets in 6 languages, the draft of the sponsorship file, the national experiences of the HH awareness Day, the constitution of a Scientific Committee and the preparation of the European HH Day in 2011.

**Remember the next EFAPH General Meeting will take place in September 2011 according to the next EIC meeting in Belgium (Leeuwen near Brussels).**

Date : December 5, 2010





Barbara BUTZECK  
(President)



Françoise COURTOIS  
(General Secretary)