

## MINUTES OF THE 8<sup>TH</sup> ANNUAL GENERAL ASSEMBLY Rennes – August 31<sup>st</sup>, September 1<sup>st</sup> 2012

Report : Françoise COURTOIS, Barbara BUTZECK, Jean-Daniel KAHN : November 2, 2012

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Agenda : **Appendix 1**

**In Attendance:** BARDOU-JACQUET Edouard (France), BRISSOT Pierre (France), BUTZECK Barbara (Germany), COURTOIS Françoise (France), DISTANTE Sonia (Norway), EVANS Robert (UK), KAHN Jean-Daniel (France), Mc GRATH Ann (Ireland), LECORFEC Alexandre (France), LOREAL Olivier (France), MULLETT Margaret (Ireland), PORTO Graça (Portugal), RIALLAND Jean (France), RYAN John (Ireland), SANCHEZ Mayka (Spain), SORRILL Robert (Italy), TOSKA Ketil (Norway), VARKONYI Judith (Hungary)

**Apologies :** ALTES Albert (Spain), DE MAEGHT Stéphane (Belgium), FERNAU Janet (UK), HORN Gerda (Switzerland), PINEAU Brigitte (France), SAILLEZ Anne (Belgium), ZOLLER Heinz (Austria).

**Invited :** EVANS Patricia (UK), HYDER Robert (UK), KREMP Odile (France), MAY Alison (Wales, UK), ROMBOUT Eva (Netherlands), SEVERN John (UK), TEIXEIRA Emerencia (Portugal), WHITE Desley (UK).

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**Welcome by Pr. Pierre BRISSOT** who is particularly happy to accommodate the AGM of EFAPH in his Liver Diseases Department in the Hospital-University of Rennes.

**Opening** of the meeting by the President **Barbara BUTZECK**, who reminds to the audience the historic location in Rennes where EFAPH was founded by Jean Rialland in 2004 and the second meeting in 2005 in Rennes as well when many of the represented national associations joined EFAPH. Barbara warmly welcomes the invited speakers Prof. Odile Kremp, France Orphanet INSERM, Emerencia Teixeira, University of Porto Portugal and Alexandre Le Corfec, AHO Brittany France. Barbara forwarded greetings from the excused members Gerda Horn, Switzerland, Brigitte Pinneau, Paris, France and Heinz Zoller, Munich, Germany (former Innsbruck, Austria). Barbara gratefully mentioned the financial support of EURORDIS regarding the realization of this AGM of EFAPH.

**Françoise COURTOIS** regretfully reminds the death of Pr Jean-Paul MOISAN , specialist in medical genetics who died accidentally last august in France, appreciating his great contribution to EFAPH and its development over the years.

### Friday afternoon session: Annual General Meeting

#### I. “Doctor-on-a-Chip” Project – Pr Robert Evans (Appendix 2)

Rob has joined the “Doctor-on-a-Chip” Project in 2011 at the Centre for Electronic Systems Research at Brunel University. The handheld device (Doc-LAB) which is under development is intended to allow the automatic and fast diagnosis of several diseases. The starting points are various samples (blood, saliva, urine, swab) and integrates biochemical and genetics tests (DNA extraction, isothermal amplification and detection). It is contemplated to analyse saliva samples in order to identify people who carry the HFE gene and thus to detect genetic haemochromatosis.

In the course of the discussion: Dr Mayka Sanchez and Pr Graça Porto point out that special attention should be brought to preserve the high confidentiality of genetic advice, the reglementation being very strict and implying the consent of the patient. The identification of heterozygous should not be the

target. Pr Pierre Brissot considers that this orientation is highly interesting and that one should consider all possibilities to use the new technologies.

## **II. Hyperferritinemia, not related to HH Type 1 – Pr Pierre Brissot (Appendix 3-extract)**

Pierre first gave an overview of acquired hyperferritinemia (iron intake, e.g. post transfusion), dysmetabolism syndrome, alcoholism, inflammation, liver diseases...).

Taking case reports, he then described the different rare forms of genetic hyperferritinemia non-HFE-related. The approach to differential diagnosis has been illustrated by “diagnostic trees” for the different occurrences, highlighting Ferroportin-disease, hereditary aceruloplasminemia and Ferritin-cataract-Syndrome .

## **III. Listening to the Patients’ voice: the first European survey on genetic information – Emerencia Teixeira- Pr Graça Porto (Appendix 4)**

The aim of this European survey was to determine which sources are used by patients to find general information about HH, what is their preference to get that information and which sources they trust more.

Via local coordinators nine member associations participated in the online posted survey which covered 1032 subjects, of which 895 where exploitable (58% males, 42% females). Of the analysed population 70% considered to be sufficiently informed about genetic testing. The preferred sources of informations about genetic testing and its implication for their health were the family doctor and the specialist, which corresponds also to the actual information sources. The same implies for the more trusted information sources. In conclusion a significant proportion (30 % of the subjects) do not feel informed about the genetic test and its implications. In general, patients prefer having information about the genetic test from their family doctors although they still trust more specialists.

## **IV. Follow-up on EP lunch-debate: Raising GPs’awareness, Developing “observatories” – Françoise Courtois (Appendix 5)**

The event took place in Brussels on 09/20/2011 at the European Parliament. The preparation took one year with the objective of raising awareness of Authorities and of Health Professionals at EU level. The results were:

A “written question” signed by MEPs of the ENVI Committee and addressed to the European Commission. The question was: “Does the Commission consider :

- taking initiatives to promote the early diagnosis of HH (programmes for raising awareness and information of the general population and of health professionals – general practioners)?
- promoting research on genetic diseases?”

The « Reply from the European Commissioner Mr. Dalli” (February, 2012), considered as very qualified by the concerned MEPs:

- The Commissioner agreed that HH is indeed underdiagnosed,
- The knowledge of the prevalence and penetrance of HH must be improved by clinical and epidemiological research,
- The role of the Commission is not to issue guidelines for the early diagnosis of HH,
- There should be room in the future European financing programmes (FP7 and FP8, 2014-2020).

*A real opportunity for EFAPH! Hence some medium and long term projects!*

Consequently, the concept of “Observatories” was developed with a view to mobilize GPs and to federate them by linking the observatories and building an ERN (European reference Network). A field pilot experiment followed in the Yvelines department (France). The Hepatology department of a “major” hospital (Dr P.Colardelle – Hôpital Mignot- Versailles) has been inventoried as a starting point. Parallely the population and the corresponding number of GPs have been quantified, their location, and the four other hospitals supporting hepato-gastro-enterology activities. A first set of indicators (number of GPs having referred at least one patient for iron overload, their location, diagnosis, ...) have been defined. The level of knowledge of the medical students has been evaluated. The detail results are available in appendix 5. The following step will be to extend the scheme to the 4 other hospitals. Parallely, a training information programme will be developed through the GPS groupings. It is contemplated to extrapolate this model to other departments.

## **V. Status and Recommendations of Reference Centres in the European Union – Pr Odile Kremp –(Appendix 6, extract)**

Historically, about 10 years ago, the need for patients to be able to benefit of adequate treatment in other countries in the EU (cross border mobility) initiated the concept of European Centres of Reference (ECR). Progressively, around DG Sanco, the idea of European Reference Network (ERN) has emerged (particularly important for Rare Diseases). A number of pilot projects were started in 2006 on various pathologies and in different countries.

Between 2006-2009 France implemented a first Rare Disease Plan and the corresponding structure as well as guidelines. At European level this resulted in the creation of the European Committee of Experts on RD (EUCERD) in 2010. The results have been quite positive in terms of patients’ satisfaction. For the 2011-2014 Plan, 2 working groups have been created to evaluate the expertise centres and to improve the care networks. The progress of the different countries is shown on the maps as per appendix 6. Further the EUCERD issued in 2011 Quality recommendations for RD Expertise Centres in member countries.

Parallely the EU Parliament and Council issued a Directive on Cross border healthcare (March, 2011). The transposition process in the national legislation is underway (targeted date october 2013).

More information is available on the following sites:

### **Cross Border Health Care Directive implementation**

[http://ec.europa.eu/health/cross\\_border\\_care/policy/index\\_en.htm](http://ec.europa.eu/health/cross_border_care/policy/index_en.htm)

### **EUCERD recommendations**

<http://nestor.orpha.net/EUCERD/upload/file/EUCERDRecommendationCE.pdf>

### **Official Journal of the European Union**

<http://publications.europa.eu/>

## **VI. Blood letting and blood transfusion in Europe – Pr Graça Porto**

Graça reminds the related ethical issues : nor obligation, neither right for the patients to donate therapeutic blood for transfusion. The last status available has been published by De Buck and coll. in Hepatology, 2012, May 30: HH patients (who do not suffer from complications) blood letting is compatible with transfusion but there is need to harmonize the blood donor selection policy among countries. Graça reminds the overview of the 1991-2001 decade by **Adams and Barton, Blood, 2010 Jul 22; 116 (3): 317-25**. The Council of Europe issued recently Blood Transfusion and Transplantation Guidelines but with no reference about HH subjects.

Graça has contacted the EC working group (2011-2012), while Françoise Courtois contacted the European Blood Alliance.

The Blood Transfusion Committee will put the matter on the 2013 agenda (Dr Marie-Emmanuelle Behr-Gross).

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## Saturday morning session: General Assembly

### I. Activity report 2011-2012: Françoise Courtois, Barbara Butzeck (Appendix 7)

- The highlight: of the year has been the lunch-debate (September 21, 2011) in the European Parliament and the brain storming of the follow-up.
- The Executive Committee has met 6 times: November 4<sup>th</sup>, 2011 (Croissy s/S), January 26-29<sup>th</sup>, 2012, Croissy s/S), April 10<sup>th</sup>, 2012 (Telephone Conference), May 15<sup>th</sup>, 2012 (Telephone Conference), May 21<sup>st</sup>, 2012 (Telephone Conference), August 25-29<sup>th</sup> Perros Guirec (France). The main decisions covered the finances and fund raising, the allocation of EFAPH representations, the planning of communication and actions, the follow-up of the EP lunch-debate.
- Finance and accounting: the details will be covered in the financial report. Noteworthy are: the transfer of the accounting to Paris, the change of the bank, the withdrawal of sponsors (Novartis, IGNA), the search for new grants (Arthritis Foundation, Ireland Fund of France, Network Ireland), Automobiles Peugeot, Eurordis, Cardinal.
- Further to the requests of the last General Assembly, the statutes have been up-dated (J-D Kahn in cooperation with a jurist and a lawyer) : English is the official working language of EFAPH, the Board and Executive Committee are elected for 2 years, the members representatives have 5 votes rights, the individual members have 1 as well as the Founder Honorary members. The new statutes have been registered by the French Administration (May 4<sup>th</sup>, 2012, sous-Préfecture Saint Germain en Laye).

### The changes in the statutes are unanimously approved

- The Communication actions have been pursued: cooperation with YLB Conseil, participation to Celtic dinners (including contacts with the Irish community and with the Celtic Diaspora), sporting event (golf de Cicé-Blossac, Rennes, October 7, 2011). Planned, charity concert in Paris by pianist Anne Queffelec (February 21, 2013). A promising cooperation has been started with Anne Quéméré, a famous French Brittany sailor, who has accepted to carry the image of EFAPH.
- The efforts to pursue the relationship with health organisation partners: European Patients Forum (EPF), Eurordis, health First Europe (HFE) and European Haematology Association (EHA).

- Several presentations have been given on behalf of EFAPH: Frontiers in Haemochromatosis, B.Butzeck, London, 10/10/2011 – Six European Conference of RD F.Courtois Brussels 05/24/2012 – EIC meeting, B.Butzeck, Rennes 08/30/2012.
- The lunch-debate in the EU parliament (Brussels, 09/21/2011) has been a success. A Written Parliamentary Question has been signed by 5 MEPs of the ENVI Committee in December 2011 (**Appendix 7-a**), the official answer from the European commissioner Mr John Dalli has been received in February 2012 (E 012656/2011, **Appendix 7-b**). The follow-up includes amongst others: “HH Observatories” including a field experiment by F.Courtois in the Yvelines Departement (France), HiroNET network (G.Porto), European Reference Network (ERN).
- Future projects 2012-2013: new EFAPH members (Austria? Poland? Bulgaria?), a first Newsletter (HEMO News).  
The discussion has resulted in establishing 2 working groups:
  1. ERN European Reference network, chair: Pierre Brissot, Edouard Bardou-jacquet
  2. HH-Arthropathy: Graça Proto, Mayka Sanchez, Barbara Butzeck collaborating with Prof. Pascal Guggenbuhl, Rheumatology, Rennes

### **The activity report has been unanimously approved**

## **II. Financial report – Jean-Daniel Kahn (Appendix 8)**

- The financial report, covering the fiscal year 2011 and the 2012 budget is presented by the Treasurer.
- Before commenting the attached series of tables J-D K emphasizes the degradation of the situation in 2012, which may jeopardize the survival of EFAPH if no substitutes are found to the withdrawal of sponsors like Novartis or IGNA, leaving the Federation without recurring income. Since HH for the time being is not attractive for the pharmaceuticals industry as the treatment is not drug centered, funds raising is uncertain, even more in the current context of economical crisis.
- In 2011 EFAPH’s income (**table 3**) has amounted to € 20,835. Besides the traditional € 10,000 grant from NOVARTIS, there have been two exceptional non-recurring entries: € 4,500 from MASTERJET, a Geneva based business or private flights company; also a lottery organized on occasion of one of the Celtic Dinners has provided € 4,615.
- On the expenses side (**table 4**) for a total of € 15,010 the items details are self-explanatory. The Travel Expenses (€ 10,585) may seem disproportionate but they include hotel accommodation for the AGM and the EP lunch-debate. The membership fees (€ 175) correspond to what EFAPH has paid as a full member of EPF and EURORDIS.
- The 2011 result is an excess income of € 5,825 with a bank balance of + € 12,849 (**tables 5 and 6**).
- In light of what has been commented above concerning the shrinking income, the 2012 budget (**tables 7 and 8**) has been established quite conservatively.
- On the expenses side travel is drastically reduced (€ 1,500) but it does not include any more the travel and hotel for the AGM, the latter being budgeted at € 7,000. As mentioned previously the procedure for EFAPH to obtain the “public institution” (registered charity) status has been provisorily laid aside, hence a saving of € 2,500; instead a request for the “general interest” status (simpler and free of charge) has been filed with the French authorities.

- The income side is, alas, quite simple. We have obtained a € 1,200 grant from CEF (Council of European Federations, emanation from EURORDIS) for the AGM. CEF supports thus the European federations efforts aiming at developing the exchanges and synergies for rare diseases.
- The budgeted treasury balance (table 9) is alarming, all the more since the sponsor (initially IGNA) for the € 1,500 grant budgeted in the income table has not yet been identified. Globally (and optimistically?) EFAPH is likely to finish the year 2012 with only € 2,000-4,000 at the bank.
- J-D K wishes to stress that EFAPH benefits from quite an array of services (provided pro bono, at no charge): legal, communication, accounting, etc... (table 10 ).These are tantamount to grants because, should they be charged, it would further jeopardize EFAPH's financial profile.
- He reiterates the urgent necessity to have all members take actively part in resolving EFAPH's funding difficulties, and not only concentrating on their own national situation. Besides the membership fees to be collected in 2013 (app. € 1,500) the only identified resource is the charity concert by the pianist Anne Quefellec. In the course of the ensuing discussion, several suggestions are made, amongst which the one to seek support from the blood components and associated equipment industry. An attempt was made about a year ago with Caridian, but to no avail. All ideas and potential contacts will be most welcome.

### **The Financial Report has been unanimously approved**

#### **III. EFAPHs Expansion - new associations: Barbara Butzeck, Ketil Toska**

III.1. Barbara Butzeck reports about the progress with German talking associations and groups:  
**Switzerland:** A new national HH-association Switzerland got in contact to Barbara Butzeck in Sept. 2011. The following email exchange stopped in 2012. Gerda Horn as chair of group Zurich tried to find out its address and telephone data without success.

**Austria:** Some HH-Patients from Austria are members of HVD Germany. Barbara Butzeck started to plan a meeting in Salzburg with Prof. Heinz Zoller, former Innsbruck, Prof. Jochen Zwerina , Vienna and Prof. Christian Datz, Salzburg , hopefully in 2013. **Belgium:** The HVV, haemochromatosis association of Flanders www.haemochromatose.be got in contact with Barbara Butzeck. She will follow the contact.

III.2. Ketil Toska reports about the Nordic countries:

**Iceland** has a small group, likely less than 10 members, little or no activity, no funds. Contact person has not replied on last emails from Ketil Toska.

**Denmark:** the HH-group will have a meeting on Sept. 11th in Copenhagen. Ketil will follow the further progress.

**Sweden:** no association or group. A facebook page seems to be gone. One member from Sweden will attend the Norwegian national congress in Oct. 2012.

**Finland:** no association or group, probably due to little occurrence of HH. Several sources of information in Finish and Estonian found.

#### **IV. Reports on activities of the national associations in 2011**

##### **IV .1 Norsk Hemokromatose Forbund (NHF, Norway) - Ketil Toska**

Ketil reports about the organisation of NHF, the positive development of numbers of members from 325 in 2011 to 426 in 2012 despite the loss of several board members and regional delegates. A 12 page news letter is ready to be posted in Sept. 2012. Future activities include the national congress in October 2012, promotion campaigns in order to raise the number of paying members, newspaper advertising, enhance activity on Norwegian facebook page. Ketil describes a huge Marketing campaign in 2011/2012 , costing almost 28.000,- € with inserts in national and regional newspapers all over Norway. Ketil analyzes the

cost and benefit of the different strategies and concluded in the lessons learned. The audience was very impressed by the amount of invested money and the outcome of more than 100 new members.

The following vibrant discussion pointed out that an expensive campaign like this should not only aim on raising the numbers of members but should help to identify undiagnosed persons by describing the symptoms.

#### **IV.2 Asociación Española de Hemochromatosis (AEH, Spain) – Mayka Sanchez**

The Spanish Hemochromatosis Patients Association is composed by 202 members. In 2012 the association was very active and we celebrate for the first time the European and National Hemochromatosis Day on the 7th June 2012. This event was done in the Hospital Esperit Sant (Santa Coloma, Barcelona) and we organized several talks for patients in the morning, an expert meeting in the afternoon about hyperferritinemia, and a dinner for patients in the evening in a centric hotel of Barcelona. The event was a great success and count with the participation of more than 70 persons. Dr. Altes (president of the AEH) was interviewed on a national TV channel and the event was announced by the press and a local radio. The Association made a Manifest to encourage the Blood Bank to use the blood form Hemochromatosis Patients. We will continue organizing this type of relevant event next year implementing other activities with more patients' participation. In addition to the AEH magazine, in 2012 the association prepared, sent and collected the data from a patient's survey to know the patients' needs, requests and satisfaction about our organization. The association created a sub-delegation in Madrid. Our next General Assembly will be in Barcelona in December 2012.

#### **IV.3 Associação Portuguesa de Hemocromatose ( APH, Portugal) - Graça Porto**

Graça illustrates with diapos the main events organized during the European HH week (06/06-10, 2012): Medical doctors workshop, manifestation TV broadcast, public genetic workshop, various outdoors gatherings, APH members lunch, posters on Facebook and APH website...

The Board of APH has been renewed. The main targets for 2012 include to continue raising HH awareness, to organize again the European HH week and to promote a new law on Users Fees.

#### **IV.4 Hemokromatozisos Betegek Eyesülete (HBE, Hungary) - Judit Varkonij**

In the last 2 yrs HBE has started to grow slowly. The number of the members doubled. This could happen regarding media activities, like having interwievs on the national TV chanel and on the radio, appearance on the Semmelweis University homepage and to the published coloured material in the most frequented womens journal .The Awareness Day was organized for the 2<sup>nd</sup> time in the first week of June and HBE participated at the Day of the Rare Diseases. A new homepage of HBE is now available and contains different informations for the patients (treatment, biological controls, blood letting, ...) and questions/answers with an expert. In Hungary HH patients officially can not become voluntary blood donor (VBD) but some initiatives are at present in progress. Actually, the HH patients who can not undergo blood letting and need iron chelation therapy might get DFO in a financially supported basis; for the other chelators an inquiry to the insurance company is also possible.

The funding for a research project was allowed to the Central Laboratory in Semmelweis University 3rd Department of Internal Medicine to conduct a large screening of 15.000 inhabitants of one district (from 2009-2011). The basis of the screening was: liver enzyme elevation and those who had also Tf saturation level (46 %) were invited through the GPs for a visit to Judith's office for a final diagnosis.

In the last 2 yrs Judith was invited to talk about the newest achievements in the diagnostic and therapy of inherited iron overload diseases.

#### **IV.5 Associazione per lo Studio dell'Emochromatosi e delle Malattie da Sovraccarico di Ferro (Italy) - Robert Sorril**

This year has been marked by a fall in the Association's income and by concern about the stability of the Iron Metabolism Clinic at Monza hospital. Despite a small increase in the number of contributing members, the money received from individual contributions and from the nominated charity element of national income tax has diminished, and corporate sponsorship has disappeared completely. Nevertheless, the Association is providing the funding for a research project (€ 5500) and for an increase in the working hours of the secretary at the Clinic. A seminar on Iron Accumulation Diseases, held at the University of Milan Bicocca, has also been supported in part by the Association. The research project, which is concerned with Hyperferritinemia without iron overload, will also be taking place at the University. With regard to the operation of the Clinic at Monza, the Association has met with the Hospital's authorities to express concern about temporary short-term contracts of work for the medical staff. A permanent position, albeit with responsibilities for other iron-related disorders as well as haemochromatosis, has subsequently been defined by the Hospital and, bearing in mind the current economic climate, this is a reasonably satisfactory outcome. Awareness Week activities were carried on 4th (Market Day) and 10th June in Monza where the Association had a stall handing out information – and our +Fe balloons! – together with advice where necessary. Participation in last spring's meeting of The Friends of Telethon (a television charity programme) may hopefully provide the Association with further opportunity to get the message across.

#### **IV.6 The Haemochromatosis Society UK- Robert Evans**

Rob Evans, as representative of the Haemochromatosis Society UK (Director Janet Fernau), concentrated his talk on three main issues: 1-The Continuing Professional Development (CPD) National Conference: Haemochromatosis 2011, held in October in London with over 120 attendees. 2- The progress in cooperation with the National Blood Service (NBS) such that from November 2012 onwards, HH-patients in maintenance phase, who meet the requirements for being a donor, will be able to donate at intervals of 6 weeks. 3- The hope that the Haemochromatosis Society UK will take part in future HH awareness days/weeks, following a "personal" article in a national newspaper by a UK journalist who was recently identified as being a HH-patient.

#### **IV. 7 Irish Haemochromatosis Association (IHA, Ireland)- Margaret Mullet**

Margaret summarizes the ongoing work of IHA (information meetings, participation to the Mini Marathon, negotiation with Health Dpt., brochures distribution, newsletter, stand at the national Ploughing Competition).

Margaret and Brendan Keenan have received the Healthcare Innovation 2012 awards. IHA negotiates with the Ministry of Health to streamline the access to venesection, reduce costs and promote blood donation. The 3<sup>rd</sup> awareness day (May 31<sup>st</sup> 2012) included TV and radio broadcasts, articles in regional and national newspaper, 38 information stands across the country. 20,000 HH patients have been diagnosed, there are 20,000 more to be diagnosed; IHA communication goals include to improve treatment facilities, to reach equity in venesection access, to raise the awareness of the Medical profession to the need for early diagnosis and prompt treatment.

#### **IV.8 Haemochromatose-Vereinigung Deutschland (HVD, GER) - Barbara Butzeck**

Barbara titled the situation in Germany with the slogan: "Same procedure as every year", explaining that members of HVD are satisfied with the regularly meetings over the country with exchange of experience and talks from experts, highlight was one weekend in April 2012 in Dresden. HVD Members voted for a continuation of the annual membership fee of 50 €. The repetition of a history of a HH-patient on TV (<http://www.ndr.de/flash/mediathek/index.html>) 4 times last year leads to some new diagnosed patients and new HVD-members. Following EFAPHs progress the HVD will apply for membership at the national

rare disease organization ACHSE and will take new approach to the national organization of GPs. In 2013 the HVD will participate in an event in Cologne for the Rare disease Day, a new brochure on low-iron diet is planned as well as a meeting of the scientific committee.

#### IV.9 Fédération Française des Associations de Malades de l'Hémochromatose (FFAMH) - Françoise Courtois (as deputy for Brigitte Pineau)

A year of hardship due to the loss of their much regretted President Jean Louis BALAGAYRIE led FFAMH to dismiss their webmaster for financial reasons in November 2011. Unfortunately their website crashed shortly after the dismissal depriving them of their most precious communication tool for a year.

FFAMH is now back on track: the board was renewed and the entry of Joel DEMARES, AHO President, is much appreciated. Monthly conference calls involving FFAMH 12 board members have been established so as to promote discussion on the implementation and progress of their projects.

Focusing on communication has been FFAMH priority through 2012 with the release of an issue of "Savoir Fer" magazine in May, the design of their new website which should be put on line at the end of 2012, and a prospective communication campaign targeting French 110 000 GPS.

#### V. The AHO Experience- Alexandre Le Corfec - AHO Vice President, France (Appendix 9)

Françoise introduced Alexandre, vice president of the Regional Association of Brittany and stressed she had required that the experience of AHO, an active and dynamic association, should be presented so as to serve as an example to some national associations.

Alexandre expressed Joel Demares (AHO President) regrets at being held back by a family event planned long ago and read Joel's greeting.

After stating AHO position in the structure of the French Federation (FFAMH, chaired by Brigitte Pineau, comprises 5 regional associations), and the way they operate in seven departmental delegations, Alexandre presented AHO five major long term actions:

1. Involvement of pharmacists to educate the general public with the help of the **CERP Bretagne Pharmaceutical Distributor**: A major action with the sending of an information file (letter, leaflets, flyers ...) to a network of 1,700 pharmacies relying on the CERP. This action funded by the CERP, was conducted in 2011, renewed in 2012, and evaluated by AHO. The campaign was largely publicized in the region (conferences, media).
2. Setting up of a mainstream communication campaign through medical laboratories in collaboration with the Regional Haemochromatosis Association of Loire (Josette Poupineau, President), supported by the **trade Union of Biologists** in these two French regions. This action started in 2012 (382 medical laboratories, 517 biologists) and will be extended in 2013 to the 7 departmental delegations.
3. Implementation of a **promising partnership with Malakoff Mederic** Group (Insurance Company with 40, 000 recipients among whom 40-70 year olds). Seven conferences (with the participation of Pierre Brissot) in 2012/2013 contributed to raise awareness in the Brittany region and to significantly increase membership.
4. Devising of a "turnkey" file to carry out a **large awareness campaign targeting doctors, staff in outpatient treatment centres and the general public**. The files were dispatched to Brittany hospitals and medical practices by the 7 delegates AHO numbers in Brittany. The impact of the 2011 campaign (renewed in 2012) is being assessed.
5. Various sporting and cultural events have been planned (or are planned) in 2012 to complement this large information campaign.

## **VI. Cooperation with European Hematology Association (EHA) – Graça Porto**

Graça Porto reports about the contacts to EHA which started in November 2011 by an invitation to the **EHA Meeting with Patient Organizations** at the ASH-Congress in San Diego Dec 2011. Graça attended this meeting as representative of EFAPH. She emphasizes that the patient advocacy is increasingly promoted by the American Society of Hematology ASH and EHA, two big international scientific societies. The meeting at San Diego showed that misdiagnosis is a common concern under patient organizations in the field of hematology diseases and cancer. The advocacy track at the EHA congress will concentrate on the interactions between patients and clinicians and researchers, including the GPs. For the EHA congress in June 2012 at Amsterdam the topic "Quality of life. Different perception between patients and clinicians" was approved; as well as "Access to standard drugs" for the ASH-EHA meeting in Dec. 2012. Further a better access for representatives of patient groups to the EHA congresses was discussed and already in June 2012 some organizations took advantage of the new rules like free travel and accommodation for speakers, delegate badges for participants, free table in the exhibition area and possibility to share booth space. EFAPH distributed their leaflets in 4 languages at the collective booth. EHA promotes also collaborative advocacy work like ECPC at the European Parliament or EU funded projects.

## **VII. Conclusion and Perspectives - Barbara Butzeck**

Barbara concludes at the end of the AGM that it was a wonderful and fruitful meeting with interesting presentations from the national associations, the members of the scientific committee and the executive board. Especially looking back to the start in 2004 at the same town Rennes the great development of EFAPH must be highly appreciated. She reminds the audience to the challenging start in the morning of the meeting with the very well accepted presentation at the EIC congress ***From Expectation to Cooperation: HH-Patients and Experts in iron metabolism and diseases*** held by the EFAPH president. In the focus of the speech were mentioned the problems of HH-Patients with Arthropathy and their wish to the researchers to develop a medicine substituting Heparin, a protein lacking in Haemochromatosis. She thanks the participants for their mental support by attending the lecture.

She asks the audience to keep in mind the poor financial situation of EFAPH and calls everybody of the hemochromatosis community to be creative in ideas and activities to find sponsors.

Barbara recapitulates the two projects which were established at the AGM:

### **1. ERN European Reference network, chair: Pierre Brissot, Edouard Bardou-jacquet and the collaboration of the Scientific Committee.**

In a first step every national association should get in contact to their Orphanet-representative on national level – asking about Reference centres for **rare forms of hemochromatosis**.

**2. HH-Arthropathy:** Mayka Sanchez, Barbara Butzeck. Graça Porto suggested to start with a survey on prevalence – epidemiology data. A collaboration with Prof. Pascal Guggenbuhl, Rheumatology, Rennes is meanwhile launched.

Closing the AGM Barbara thanks Pierre Brissot and Edouard Bardou-Jacquet for the local organization. She expresses a big thank to the founder and honorary president Jean Rialland for his tremendous contribution to the meeting by offering taxi – like services almost 24 h for the last 4 days in and around Rennes for all participants. Many thanks also for the 1,200€ grant from CEF (Council of European Federations, emanation from EURORDIS) for their support for our AGM.

At last but not least Barbara appreciated the outstanding effort of Françoise Courtois by organizing and managing the hotel accomodation, the coffee breaks and Saturday lunch besides her official contribution as General Secretary with several interesting presentations.

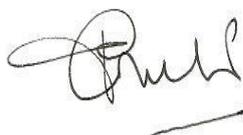
The EFAPH General Meeting in 2013 will take place **April 19<sup>th</sup>, 2013** in the frame of **the Biolron meeting April, 14 – 18, 2013 in London, UK.**

**Preview: EFAPH AGM end of August 2014 in Verona, Italy** in the frame of the EIC congress.

**Date: November 4<sup>th</sup> , 2012**



**Barbara BUTZECK (EFAPH President)**



**Françoise COURTOIS (EFAPH General Secretary)**

