



EUROPEAN FEDERATION OF ASSOCIATIONS OF PATIENTS WITH HAEMOCHROMATOSIS
FEDERATION EUROPEENNE DES ASSOCIATIONS DE MALADES DE L'HEMOCHROMATOSE

MINUTES OF THE SEVENTH ANNUAL GENERAL ASSEMBLY



BRUSSELS – SEPTEMBER 8TH 2011

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MINUTES OF THE SEVENTH ANNUAL GENERAL ASSEMBLY

Brussels – September 8th 2011

Report : Françoise COURTOIS, Barbara BUTZECK, Jean-Daniel KAHN : november 15th 2011

In Attendance: BRISSOT Pierre (France), BUTZECK Barbara (Germany), COURTOIS Françoise (France), DE MAEGHT Stéphane (Belgium), EVANS Robert (UK), HORN Gerda (Switzerland), KAHN Jean-Daniel (France), Mc GRATH Ann (Ireland), MULLETT Margaret (Ireland), PINEAU Brigitte (France), PORTO Graça (Portugal), RIALLAND Jean (France), SAILLEZ Anne (Belgium), SANCHEZ Mayka (Spain), SEVERN John (UK), SNYERS Anne-Sophie (Belgium), SORRILL Robert (Italy), TOSKA Ketil (Norway), WHITE Desley (UK), ZOLLER Heinz (Austria), Jochen ZWERINA (Austria).

Apologies : ALTES Albert (Spain), COSTA Joao Manuel (Portugal), FERNAU Janet (UK), KUN Levante (Hungary), MULLANEY Frances (Ireland), RYAN John (Ireland), BOSTEELS Marina (Belgium), VARKONYI Judith (Hungary).

Invited : ATZORI Walter (EPF, Brussels), BARDOU-JACQUET Edouard (France), DOOLEY Ann (Ireland/Belgium), LOREAL Olivier (France),

Guests : EVANS Pat (UK), HORN Reinhard (Switzerland)

Opening of the meeting by the President **BARBARA BUTZECK**,

with a warm **Welcome** to all participants and especially the representatives of the new EFAPH members from Belgium, Italy and Switzerland. The absence of the late Dr Jean-Louis BALAGAYRI, former President of the French association was regrettably noted.

Warm thanks to Françoise Courtois who organized the meeting, Mrs. Martine ALLAIS who provided EFAPH with the assembly room at the Permanent Delegation of Brittany and Mrs. Isabelle KONING who was in charge for the technical facilities.

Morning session : Annual General Meeting

I. Lunch debate at the european parliament, september 20th 2011 – Françoise Courtois (Appendix 2)

Françoise Courtois outlines the long work and approach to set-up this event. This should be considered as an important step forward for EFAPH. The main objectives are to make the EU politicians aware of HH and to attempt to have an official « written parliamentary question » to the European Commission. The preparation

has included numerous meetings with EP officials and Health Attachés of the Permanent Delegations of several member states. FC points out that the lunch debate is a thrilling but « crazy » project...

All the details are included in Appendix 2 and a summary of the event will be available.

II. Projects of the Scientific Committee - Pr Graça Porto, President

Graça Porto started her talk by reminding the audience that patients and researchers need each other. Patients need researchers to get good and reliable information and researchers need patients to get awareness about their most significant problems. She suggested an opportunity for EFAPH to contribute to the preparation of guidelines for molecular genetic testing in the frame of EMQN (European Molecular Quality Network). In her opinion, EFAPH could participate in the first European survey on the patients' perception about genetic information. She ends her talk with a picture of an orchestra to allegorize the scientific committee in the stage of tuning their instruments in order to start playing the real music.

The suggestion of Pierre Brissot to include Olivier LOREAL as a new member of the Scientific Committee was warmly accepted by the audience.

III. What is new about HH - Pr Pierre Brissot

Pierre Brissot reports from the international liver conferences EASL and AASL in 2011 as well as from the Biolron in Vancouver, May 2011. Regarding epidemiology of HH he quoted two reports from Brazil and Romania. Concerning the mechanisms participating to HH expression, he mentioned several co-factors such as TMPRSS6 (Finberg), an inhibitor of hepcidin ; MCP 1 (Muckenthaler), and Lymphocytes CD8+ (Porto). There was also an interesting article revealing the coherence of HH and osteoporosis. Regarding diagnostic aspects of HH, Pierre noted two rheumatology studies about efficacy of phlebotomy and lowering of Transf.sat. (Larty, J.Clin. Rheumatology) and one about hip replacement by Gurrin. Another interesting work on Hepcidin determination was published in Journal of Hepatology by Kroot. In the field of treatment publications about Deferasirox as an alternative to phlebotomy by Phatak (Hepatology) and about the technique of Erythrocyte Apheresis by Rombout-Sestrienkova (Transfusion, in press) were mentioned. Very interesting but so far in the phase of tests in mice is the development of mini-hepcidins as an oral or injection medicine (Ganz). Pierre finished his talk by a wink, with a zoological therapy by... leeches, published in Br.J. Haematology by Nagler.

IV. Muskuloskeletal manifestations of Hereditary Haemochromatosis - Pr Jochen Zwerina

Jochen Zwerina open his talk with an overview about epidemiology, genetics, penetrance and diagnostic strategies in HH. Then he presented clinical fotos and radiological findings of HH-Arthropathy which are quite similar to osteoarthritis (and pseudogout, CPPD) and differentiate only in some joints regarding the pattern of the diseases. However the hand arthropathy of hereditary hemochromatosis is strongly associated with iron overload esp. the second and third MCP-joint and the wrist. Jochen Zwerina explained a HFE arthropathy scoring system by evaluating characteristic radiographic features at characteristic sites and an HH-Arthropathy atlas for MCP II and III, the wrist and the ankle which was published by Dallos T et al. *Ann Rheum Dis.* 2010. Zwerina presented results from a cohort study (n=144) where 72% of HH-patients are complaining joint pain, starting with mean age of 45y, 63% taking medication for joint complaints with a mean of 1474 € /year joint-related medical costs. Regarding joint replacement surgery the study revealed a mean age at first TEP of 58,3 y

in comparison to a general population without iron overload of 72,1 y. 32 (/144) HH-Patients underwent joint replacement, total No. of TEPs were 52. Female gender, chondrocalcinosis and radiographic MCP II + III scores were found out as risk factors for joint replacement surgery. Concerning the therapy of HH-Arthropathy Jochen explained the 4 columns: NSAID (pain, inflammation), physiotherapy (joint function), nuclear medicine (radiosynoviorthesis) and surgery (Synovectomy, arthrodesis, joint replacement).

V. Funding opportunities for patient groups under the Structural Funds – Walter Atzori - European Patient Forum
(Appendix 3)

Walter Atzori (WA) presents the structure and objectives of EPF. He points out that there are opportunities, under certain conditions, for associations to benefit from EU Structural Funds which are managed directly by the member states or the regions. EFAPH and its members should consider to apply for the next programming period (2014-2020). The details are available in the Appendix 3).

The matter is complex and EFAPH will consider to file an application, depending on the outcome of the lunch debate. It is very likely that EFAPH's national member associations will have to be involved. WA is available for advice.

VI. Reports of National Associations

- 1) UK : Robert Evans** introduced himself as Scientific Advisor and representative of the Haemochromatosis Society UK Director : Mrs. Janet Fernau, MBE. The British Association has more than 1000 members, the membership fee is 10,- £. He announced the upcoming conference « Haemochromatosis 2011 » in London (Monday 10 October 2011) organized by the Haemochromatosis society UK. 120 participants are expected to come : medical doctors, nurses and patients. Speakers include experts of hepatology, genetics, rheumatology, haematology, endocrinology, molecular biology and medicine, as well as patients and nurses.
- 2) Portugal : Graça Porto** gave a short overview about the foundation of AHP in 2003 (10 members) and the progress until 2011 with 75 members. She reported from the haemochromatosis day on June 7th, 2011 which was organized with the support of the team « communication in Science » of IBMC. A focus group of HH-Patients and health professionals was formed. Actual reports were placed on « O grande Porto » online and on RTPN the North channel television. The focus group raised as main questions: poor knowledge of GPs about the disease - poor "trustful" information about the disease - fear about future "cuts" in the health care budget. GPs and General public were identified as target groups. The objectives were the implementation of TfSat in routine tests, and the motivation of Health authorities. As available tools the APH website, personal experience (in the form of testimonials) and direct contacts between APH and health professionals were pointed out. Finally a list of proposed actions to be implemented was elaborated.
- 3) Switzerland : Gerda Horn** presented the first Selbsthilfegruppe für Hämochromatose in Switzerland. The group is located in the canton Thurgau in the North-east of the country. Currently the group has 15

members. They meet each other every two months. Gerda described her attempts to expand the group throughout the whole country. She also mentioned the difficulties to get an adequate medical care.

- 4) **Germany : Barbara Butzeck** shortly presented the history, structure and organization of the Haemochromatose-Vereinigung Deutschland HVD. She pointed out that the highlights for HVD in 2011 were publications in magazines and patient reports in regional television programmes with a good feedback of spectators. The message from members of HVD to EFAPH is to step forward in achieving early diagnosis and improvement of therapy of HH-arthropathy which is a major factor of poor life quality for HH-patients in Germany.
- 5) **Italy : Robert Sorril** presented the Haemochromatosis Association of the Italian region around Monza which celebrated its 15th anniversary. Honorary member is Pr Alberto Piperno, Director of the Centre of excellence for haemochromatosis in Monza who represented the association at the IAHA meeting in Vancouver. The Italian association has 150 members. They do not have a fixed membership fee, but ask for donations, suggesting 25 €. Robert explained that in Italy exist more rare forms of HH. Following the call of EFAPH the Italian group organized several informative actions during the HH awareness week : during 2 days they had an information stand on a market in Monza, where many families showed their interest. The group distributed information material in pharmacies and organized a telephone service.
- 6) **Spain : Mayka Sanchez** gave a short overview about the history of AEH. Currently the association has 184 members, the headquarters are located in Barcelona. A diagram outlined the HH diagnosis procedure in Spain, where there is an advanced genetic service on iron hereditary diseases (esp. rare HH forms and iron deficiencies) at IMPPC. The recruitment of patients was reinforced by the creation of the Iberian group of Iron disorders by Albert Altes and Mayka Sanchez (61 medical doctors/researchers and 43 hospitals/centers throughout Spain). AEH activities in 2011 included meeting Mr Francisco Sevilla Perez (Spanish Health Attaché in Brussels), 3-4 Patient's Newsletters/year, a meeting with lunch for HH patients late september 2011 and the preparation of a Spanish awareness HH day in 2012.

Mayka then reported 2 interesting cases of rare HH- mutations and the results of her thesis, a population screening done 2003 in >5000 blood donors from which the estimated number of HH-Patients with classic HFE mutation in Spain was 52.200 persons. (1: 1000 C282Y/C282Y and 1: 100 C282Y/H63D).
- 7) **Ireland : Margaret Mullet** illustrated the activities of the Irish haemochromatosis association IHA (1600 members) by distributing the last newsletter. The HH awareness day on June 2nd 2011 was a great success : information stands in 34 town centres (including a ploughing championship in Sept. 2010 attended by 180.000 people), articles published in the Irish Times, Examiner and Daily Mail, several interviews on National TV and Radio. Furthermore brochures were distributed to all GPs nationwide, to pharmacies and libraries. A National Treatment Programme was submitted in August 2011 to the Health Service Executive (HSE). After agreement and sign-off a Clinical Advisory Group will be set up to establish National Treatment Guidelines with input from GP's, HSE, haematology, the Irish Blood Transfusion Service (IBTS); it will begin at local clinics in order to increase the number of treated HH-patients by 50 %. Some experiences of fund raising in the last year were presented. Margaret expressed her warm thanks to Frances Mullaney for her invaluable work for the IHA and EFAPH. She resigned from the IHA and EFAPH Boards because of her occupational activity in London.
- 8) **Norway : Ketil Toska** reported the good progress made in Denmark and Sweden.

VII. International Alliance of HH Associations (Vancouver)

Barbara Butzeck attended a satellite meeting of the Biolron in Vancouver in May 2011 with representatives of HH-Patient organizations from Europe, Canada, Australia and USA. The main result has been to launch an International Alliance of Hemochromatosis Associations (IAHA). The participants agreed on the organization of a yearly "HH world day" and on a very preliminary version of proposed statutes. The leadership of the alliance should be for the first 2 years term the Canadian Hemochromatosis Society (CHS). The IAHA should have an independent structure but will remain close to the IBIS society with meetings every two years in the frame of the Biolron congress (next April 2013, London), and will be officially represented at the IBIS Board.

Afternoon session : General Assembly (list of attendance : *Appendix 4*)

I. Activity report 2010/2011 - Françoise Courtois -General Secretary : Report covering the period September 2010 – September 2011

- The Executive Committee has met 6 times : December 3rd 2010 (Croissy S/S), February 7th 2010 (Croissy S/S), March 24th (Brussels), May 2nd (Telephone conference), June 19th and August 30th (Croissy S/S). The minutes have been emailed to the members and are available on request. The main decisions covered the finances, the website renewal, the allocation of EFAPH's representations, the planning of communication and actions, the preparation of the lunch debate.
- Noteworthy is the cooperation with the Communication Consultant YLB Conseil, who provided significant help on a *pro bono* basis. Moreover an agreement has been signed with respect, particularly, to fund raising. The major contacts have been mentioned : most of them are in France and it is desirable that the association members in other countries involve themselves also.
- Significant efforts have been dedicated to maintaining or starting the relationship with health organisation partners : EPF, Eurordis (in spite of a divergence on the concept of rare disease), DIA (Drug Information Association), HFE (Health First Europe), Fondation Roche, Management Centre Europe (MCE), ...
- Particular attention has been given to the membership : new members (Switzerland and Belgium), reactivation of UK and Italy (new representatives at the General Assembly) ; promising contacts with Denmark, Austria and Poland.
- A strong participation of EFAPH at the IBIS (International Biolron Society) Congress in Vancouver, Canada (May, 2011) has been instrumental in laying the foundation for the International World Alliance (see presentation by BB).
- An important administrative procedure has been undertaken by JDK and FC with the *pro bono* help of a lawyer (status of registered public charity – see presentation by JDK).
- Considerable time and effort have been dedicated to launching the EP lunch-debate over a 12 months period (see presentation by FC).

- FC expresses the wish that the national members involve themselves much more in EFAPH's international activities, particularly with respect to the fallout from the EP lunch-debate.

The activity report has been unanimously approved by vote.

II. Financial report – Jean-Daniel Kahn -Treasurer (Appendix 5)

- The final results for the fiscal year 2010 are presented. JDK reminds that the figures cover exceptionally 15 months (10/01/09-12/31/10) because of the change in accounting period voted at the previous General Assembly. The total income amounts to 12,629.07 € whereas the total expenses amount to 15,226.57 €, with 2 major items: printed material (sponsorship file, leaflets...) around 4,700 € and travel (AGM, Executive Committee meetings...). The resulting 2010 deficit amounts to 2,597.50 €. However the treasury balance is good (7,023.75 €), thanks to the surplus from previous years.
- The forecast for the fiscal year 2011 (8 months actuals+4 months estimates) was then presented. Total expenses are expected to amount to 21,529 €, the major item being travel, with a sharp increase to nearly 17,000 €. The total income is expected to amount to 23,425 €. The resulting income excess should be in the order of 1,900 €. JDK emphasizes a certain degree of uncertainty, particularly with respect to the grants. The treasury balance amounted to app. 7,000 € on year-end 2010, thanks to the reserves dating back to 2006-2008.
- If actuals confirm the forecast at year-end, 2011 will be the first year since 2008 (incl.) where EFAPH has no deficit. This is due in part to the successful funding efforts deployed by Françoise Courtois in France. JDK calls the attention of the General Assembly to what would be otherwise **a continuous structural deficit**.
- A first draft of the 2012 budget is then presented with a sharp increase of income and expenses amounting each to 33,000 €. JDK emphasises that to-date this budget is only indicative.

The financial report has been unanimously approved by vote.

III. Statutes renewal – Jean-Daniel Kahn (Appendix 6)

The revised statutes have been drafted pro bono by a specialised lawyer in French with the cooperation of JDK and FC, translated into English by a professional translator and e-mailed in due time to all the Members before the General Assembly.

For historical reasons EFAPH was formed in France, complying with the French law on associations (so-called "1901 law on associations"). Some changes are necessary for EFAPH to obtain **the status of association d'utilité publique ("registered public charity")** which exists under various forms in most EU member states. This status provides tax advantages to donors and thus is helpful for fund raising. This opportunity has also been taken to streamline and simplify the statutes.

The new statutes highlights are as follows:

- The structure of EFAPH (General Assembly, Administrative Board and Executive Committee) has been preserved.
- EFAPH's working language is English.
- As a difference with the draft e-mailed to the Members it is proposed to elect the Board and the Executive Committee **every 2 years** (instead of every year) **simultaneously**. **The proposal is approved unanimously by vote by the Assembly.**
- In addition to Association members, individual members can be accepted by the Executive Committee. The Association members will have two rights of vote versus one for individual members. **The Assembly approves unanimously the principle of individual members but requests the Executive Committee to change the proposed voting mode so that the Association members cannot be outnumbered by individual members.**
- Additional provisions are for formal compliance with the status of "registered public charity", e.g. the disposal of patrimonial assets.
- Some uncertainty reminds about the right of vote of the two honorary members and those members of the Board and the Executive Committee who are not representing a member country .

JDK and FC will consult the lawyer about the above.

IV. Renewal of the Board and the Executive Committee (Appendix 7)

In light of the new statutes, the new Board is elected (secret ballot) by the designated members of the General Assembly: 10 candidates for 9 positions to be provided. The points for each candidate are attributed as per article 5 of the statutes.

Composition of the new Board :

Barbara BUTZECK (Germany- MD) : 65

Françoise COURTOIS (France - MD) : 57

Robert EVANS (UK –MD,PhD) : 36

Ann Mc GRATH (Ireland) : 27

Jean-Daniel KAHN (France) : 51

Graça PORTO (Portugal - MDPhD) : 41

Anne SAILLEZ (Belgium) : 21

Mayka SANCHEZ (Spain - MD) : 49

Ketil TOKA (Norway) : 47

The new Board has then met to elect the Executive Committee.

President : Barbara BUTZECK
Vice President : Mayka SANCHEZ
Vice President : Ketil TOSKA
General Secretary : Françoise COURTOIS
Treasurer and Deputy General Secretary : Jean-Daniel KAHN

V. EFAPH Website

Barbara Butzeck presented the frontpage of the new website and exemplarily some topics of the navigation line : under « About EFAPH » were e.g. reports from the actions regarding the HH awareness week in 2011 in some countries, under « national associations » is a list of the contact data of the associations. Under « About haemochromatosis » you can find the EASL guidelines and the informations leaflet in several languages for download . Barbara pointed out that she needs input (articles, pictures, links to newsletters, announcement of meetings) from all members to make the website alive.

VI. Different questions and Conclusion

- A restricted working group is then formed to draft the guidelines in preparation of the possible “Written Question” from the MEPs to the EU Commission further to the lunch-debate. The draft will be reviewed with the Parliamentary Assistant of MEP Mrs Antonyia Parvanova.

- General satisfaction has been expressed for the progress made and the work done. The meeting has also allowed some closer and convivial contacts between the members, thus reinforcing the cohesion of the Federation.

Remember the next EFAPH General Meeting will take place in Rennes, France, probably Friday, 31st of August / Saturday 1st of September 2012 depending of the next EIC meeting 29th – 31st August 2012.

The EFAPH General Meeting in 2013 will take place in the frame of the Biolron meeting April, 14 – 18, 2013 in London.

Date : November 8th 2011



Barbara BUTZECK (President)



Françoise COURTOIS (General Secretary)



APP 1 : AGENDA

09.00-13.15: MORNING SESSION: ANNUAL GENERAL MEETING

09.00-09.15: Registration - Coffee

09.15-09.30	Welcome to all and esp. the new EFAPH members from Belgium, Italy, Switzerland and the Association in progress Denmark	Barbara Butzeck (EFAPH President)
09.30 -09:45	Lunch debate at the EU Parliament September 20 th , 2011	François Courtois (EFAPH Gen.Sec)
09:45- 10:00	Projects of the scientific committee	Pr Graça Porto (Porto-Portugal)
10:00 – 10:10	What is new about HH ?	Pr Pierre Brissot (Rennes – Fr)
10:10 – 10: 40	Musculoskeletal disease burden of hereditary hemochromatosis - Diagnostic and Therapy Options	Pr Jochen Zwerina (Vienna-Aus)
10:40 – 11:10	Funding opportunities for patient groups under the Structural Funds	Walter Atzori (Eu Patient Forum)

11.10 – 11.20 break

11:20-12:25	Reports from the activities of the national associations in 2011	
12:25-13.15	International Alliance of HH-Associations (Vancouver) > European/worldwide HH-day	Barbara Butzeck

13:15-14.25: Lunch break (Brasserie 1898 – 4 Avenue d'Auderghem)

14.30-16.00: AFTERNOON SESSION- GENERAL ASSEMBLY

14.30-14.40	Activity report 2010-2011, approval by voting	F. Courtois, B.Butzeck
14.40-14.55	Financial report, approval by voting	Jean-Daniel Kahn (EFAPH Treasurer)
14.55-15.10	Statutes revision, approval by voting	Jean-Daniel Kahn
15.10-15.30	Renewal/election of the Board (vote by general assembly) and Executive Committee (vote by administrative council)	
15.30-15.40	EFAPH Website and internet forum	Barbara Butzeck, Ketil Toska
15.40-15.50	Different questions	
15.50-16.00	Conclusion and Perspectives	Barbara Butzeck

16.00 END OF MEETING

16 – 17.30 : MEETING OF THE EXECUTIVE COMMITTEE



A Lunch Debate in the EU Parliament: A new step forward!

Dr Françoise COURTOIS , Jean-Daniel KAHN

Brussels- Annual General Meeting
September 8th 2011



Why?

- To raise the EU politicians awareness of HH
- To implicate the members of the EU Parliament (MEPs) in making the European Commission HH sensitive through a written parliamentary question (cosigned)
- To trigger actions at national level



Outline

1. Understanding the « system »
2. Design the event
3. Searching for the guests
4. How is it going to take place ?
5. The Institutional Action: Why a written parliamentary question?



Stage 1: Understanding the « system » (1)

september to december 2010

Find a entry point into the EU Parliament

- Focus on the ENVI Commission
- Select 3 or 4 MEPs « Godfathers » and... convince them!
- Learn about lobbying in this strange, hard to understand and changing world
- Decisions rarely or never confirmed...



Stage 1: Understanding the « system » (2)

Rules of the game to obtain means:

- minimum 2 MEPs of different nationalities in the same political party
- Support of the President of the ENVI Committee
- Mobilize maximum of political personalities : Envi Committee (63 deputies + 63 substitutes)...
- Obtain share of the budget of one or more MEPs with +/- participation of the ENVI Committee, minimize budget
- Find a theme of mobilizing debate....

Everything is so vague, nothing is defined
Never grow tired
Never let go !...



Stage 2: Design the event (1)

- Choose the formula: **lunch-debate** (2 h)
- Define the date: **September 20 th, 12:30-14:30 PM**
- Identify the **parliamentary targets**
- Establish a **preliminary agenda**
- Define the **budget**
Lunch, promotion, venue and materials... (MEPs)
Travels (EFAPH)
- Finalize a **calendar** and the **tasks allocation**
- Find a **top level moderator**
- Establish the **list of the guests**
- To officialize the invitation by a "Save the date"



The Agenda

1. **Welcome : Jo Leinen**, MEP, Chair of the ENVI Committee
2. **Introduction: Dr Antonyia Parvanova** , MEP, ENVI Committee
3. **Pr Pierre Brissot** : « Haemochromatosis: a highly preventable genetic and european disease »
4. **Dr Barbara Butzeck**: « EFAPH: a growing network for the benefit of patients with genetic iron overload »
5. **Dr Roland Lemye (CPME)** : How to induce the european doctors to be aware of HH?
6. **Margaret Mullett**: A patient testimony
7. **Discussion** led by a famous French journalist
8. **Conclusion: Corinne Lepage**: MEP, Vice President of the ENVI Committee

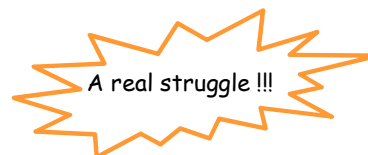
Stage 3: Searching for the guests (1)

(February to July 2011)

1. MEPs others than the "godfathers" of the ENVI Commission: 3+ 5
2. Prospecting the Permanent Delegations -> Health Attaches :

→ An essential relay of Health authorities in Brussels towards the EU countries

→ Priority to the delegations of the 12 EFAPH member countries and of country with potential (9 Health Attache/ 12 delegations)



Stage 3: Searching for the guests (2)

(February to July 2011)

3. The other guests who accepted:

- DG Sanco
- European Blood Alliance
- The Committee of the Regions
- Standing Committee of EU Doctors
- Pharmaceutical Group of the EU Union
- 1 representative of the Belgian Parliament
- The Belgian Red Cross
- European Patient Forum (EPF)
- International Diabetes Federation
- The Polish Patient Federation
- Health First Europe



Stage 3: Searching for the guests (3)

(February to July 2011)

4. The guests who have not accepted :

- Le Conseil Economique et Social
- Eurordis
- European Cancer Patient Coalition

5. The other participants

- EFAPH members (10)
- YLB Conseil (communication consultant)
- Bernard de la Villardière : top journalist moderator
- Journalists of the EU Press , ...



Stage 4: How is it going to take place?

1. A lunch-debate of 2 h
2. The date: **September 20 th, 12:30-14:30 PM**
3. A (EP) meeting room for 120 persons is reserved. The logistics are taken care of by the parliamentary attachés
4. The menu is selected (simple small buffet), paid by MEPs
5. Some communication / information documents are to be developed
6. The moderator is identified: a briefing is planned with the communication Consultants
7. The network of EFAPH (scientific committee and members) will be activated to validate the written questions MEP via the European Commission



5: The Institutional Action: What is a written Parliamentary question?

- The MEPs should commit to be the vectors of EFAPH's request to the European Commission
- It is the only way/procedure to obtain a concrete reaction of the European Commission
- EFAPH must be credible and the request must be explicit, concrete and applicable



5: The Institutional Action: What a written Parliamentary question? (1bis)

I) Information/ Sensibilization:

- a) To request that each state organizes an information campaign in the frame of the European HH week in order to sensitize the health professionals, the general public and the Health authorities. Each country could lean on : existing HH Associations, other patients Organizations and Health authorities...
- b) To include HH officially in the Universities cursus (specialized sessions...), to organize training sessions for health professionals (continuing medical education, etc...)



5: The Institutional Action: What a written Parliamentary question? (2 bis)

II) Early diagnosis:

- a) To promote Serum Ferritin and Transferrine Saturation testing:
 - following clinical warning signs
 - systematically on occasion of a first blood donation, then every 5 years???
 - and why not ... systematic testing at the age of 40 years old for males and 50 years for females????
- b) To make resources available in each country for systematic family genetic testing.



APP 3 : FUNDING OPPORTUNITIES FOR PATIENT GROUPS UNDER THE STRUCTURAL FUNDS



Funding opportunities for patient groups under the Structural Funds

EFAPH Annual General Meeting 2011

Brussels, 08 September 2011 Walter Atzori, Programme Officer, EPF

THE EUROPEAN PATIENTS' FORUM

Who are we?

- Umbrella body of 51 patient organisations
 - Pan-European disease-specific patient organisations (38)
 - National Coalitions of Patient organisations (13)
- 150 million patients with chronic conditions in the EU
- Vision:** high quality, patient-centred equitable healthcare across the EU
- Areas of work** → **Cross-cutting issues (single voice for all patients)**
 - > Patient Safety & Quality of Care
 - > Information to Patients - Health Literacy (incl. eHealth literacy)
 - > Cross-Border Healthcare and Patients' Mobility
 - > eHealth
 - > Health Research
 - > Health Technology Assessment (HTA)
 - > Pharmaceutical Package

EU FUNDING OPPORTUNITIES

Not just another funding source

EU funding is one out of many possible funding sources, but is a crucial one

- Sponsors' funding
- Fundations' grant
- Government subsidies (core grants)
- Membership fees
- Donations
-
- EU funding**

FUNDING OPPORTUNITIES

Patients organisations are newcomers in EU projects

Patient organisations have traditionally not look at EU health-related funding because:

- They are more complex and hard to obtain vis-à-vis more traditional source of funding:
 - > **Co-financing rule:** you need to have your own financial resources (or financial resources of third parties) to match EU funding
 - > **Non-retroactivity rule:** you can get co-funding only for the costs which are eligible incurred after the starting date
 - > **Time and resources needed** for the preparation are not covered
 - > Complex administrative and financial requirements

Patient organisations have traditionally not been recognised as valuable players in delivering EU health projects:

Increasing evidence that patient organisations involvement is hugely beneficial (see Clinical Trials, HTA, eHealth) – **example patient involvement in FP7**

FUNDING OPPORTUNITIES

Two different types of programmes

EU BUDGET

Programmes managed directly by the European Commission

- Public Health Programme
- FP7 for Research - Health
- Innovative Medicine Initiative
- ICT for Health
- PROGRESS – Social Inclusion
-

Programmes managed by the Member States/regions

- Structural Funds
- Rural Development Programmes
- Other minor programmes

COHESION POLICY

Cohesion Policy and Structural Fund

- **Cohesion Policy** is the EU's strategy to promote and support the "overall harmonious development" of its Member States and regions
- The **Structural Funds** are the Cohesion Policy's key financial instruments. They provide the financial resources to promote economic, social and territorial cohesion across European regions.

2 Structural Funds

- **European Regional Development Fund (ERDF)**
 - > "hard investment"
- **European Social Fund (ESF)**
 - > "soft investment"

COHESION POLICY

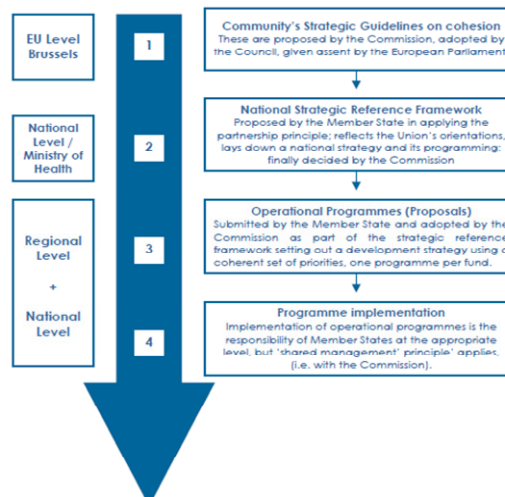
How does it work?

Two-level decision making:

European level



National/regional level



HEALTH AND STRUCTURAL FUNDS

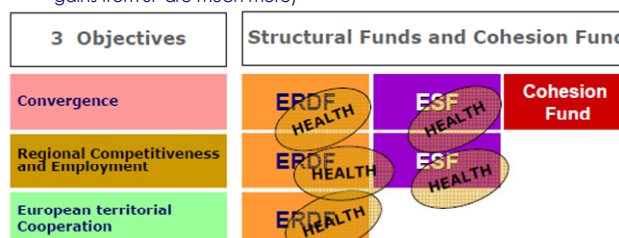
Not only health..

- **Health** was listed as a priority for Structural Funds for the first time in 2007
 - > many countries and regions are using Structural Funds to support health projects and investment
- Structural Funds invest in other areas relevant to patient organisations such as:
 - > Social Inclusion,
 - > Anti-discrimination
 - > Access to employment
 - > Education and training
 - > Urban projects and local services
 - > ..

HEALTH AND STRUCTURAL FUNDS

Health investment

- ▣ Total Cohesion Policy Budget 2007-2013: **EUR 308 billion**
- ▣ Direct Health allocation **EUR 5 billion** (but opportunities for health gains from SF are much more)



COHESION POLICY

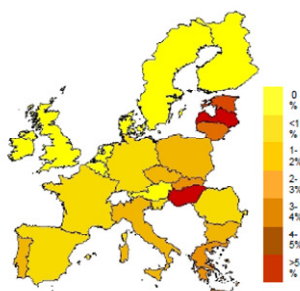
Who is using SF for Health ?

Between 2007 and 2013:

•€5.1 billion (1.5% of the total of cohesion policy funding) has been earmarked to support health infrastructure

•€5 billion have been earmarked for e-services (including e-health)

•€1 billion has been earmarked for active ageing, etc.



Health infrastructure: Percentage of planned investments in health infrastructure in relation to the total amount of Structural Funds allocated to Member States in 2007-13.

COHESION POLICY

How can Structural Funds be used for health?

1. To prevent health risks

- ▣ Education and awareness raising campaigns
- ▣ Generic health information campaigns
- ▣ Transfer of knowledge and technology
- ▣ Developing necessary skills for health services
- ▣ Funding products and equipment to prevent risks and minimise potential damage

COHESION POLICY

How can Structural Funds be used for health?

2. To improve Health infrastructure

- ▣ Screening, diagnostics, treatment (technology)
- ▣ Creating centers of excellence
- ▣ Creating Regional and national networks to share knowledge between different specialities – co-morbidities
- ▣ Access to primary care centres Information technology
- ▣ Promoting provision and optimum level of health services
- ▣ Appropriate technology, such as telemedicine and the cost-saving potential of e-health services

COHESION POLICY

Who can access Structural Funds

Who can obtain funds from the Structural Funds?

- ▣ Generally there are no restrictions
- ▣ Public, private, NGOs, voluntary sector bodies can all apply for structural funding.
- ▣ Sometimes national/regional authorities may decide to narrow down the range of entitled entities e.g. only healthcare centres, NGO's or SME to apply.

Where can I find information/apply?

- ▣ This information is published in the call for proposals as well as deadlines and required documents.
- ▣ There is no common or general application process for EU funds. The procedures are country-specific

COHESION POLICY

How do I need to approach?



European Union



Member States and regions

The **EU does not manage the Structural Funds programmes** and that the national and/or regional authorities are the only ones to grant projects at national/regional level.

It is thus not possible to apply for any Structural Funds project at the EU level

COHESION POLICY

Managing authorities

The detailed management of programmes which receive support from the Structural Funds is the responsibility of the Member States. For every programme, they designate a managing authority (at national, regional or another level) which will inform potential beneficiaries, select the projects and generally monitor implementation.

Select a country and the contact information for the managing authorities of the various programmes will appear below on this page.

Belgique - België	Danmark	Deutschland	Eesti
España	France	Ireland - Éire	Italia
Latvija	Lietuva	Luxembourg	Magyarország
Malta	Nederland	Polska	Portugal
România	Slovenija	Slovensko	Suomi - Finland
Sverige	United Kingdom	Österreich	Česká Republika
Ελλάδα - Ellada	Κύπρος - Kipros	България - Bulgaria	

COHESION POLICY

Participating in a project

• The European Social Fund:

Patient organisations could apply for/participate in various types of projects under different ESF priorities both as individual beneficiaries and as part of consortia:

- Health information campaigns
- Screening programmes
- Health literacy programmes
- Antidiscrimination measures promotion for people with disability and/or chronic condition (when applicable)
- Training for informal carers
- Access to employment and vocational training for patients
- Improving access to health services
- Capacity-building

COHESION POLICY

Funding opportunities

There might exist different opportunities for patient organisation. It is important therefore to first consider whether you are best placed to:

- **Implement a project**
 - > Manage a project
 - > Participating in a project as partner
- **Tender to deliver services under an existing project**
- **Benefit directly from a project set up to support the third sector (capacity-building)**
- **Influence investment priorities**

COHESION POLICY

National/regional decision-making

• Can stakeholders get involved?

Partnership Principle

Article 11 General Structural Funds Regulation:

Member States are required to involve all relevant partners, **including NGOs**, throughout all stages of Structural Funds from design to final evaluation

Implementation of partnership responsibility of the Member States

- > Open on line written Consultations
- > National/regional round tables
- > Ad-hoc expert committees

COHESION POLICY

...looking at 2014-2020...

Why should patient organisations get involved at both EU and national level?

- To ensure that health remains a priority for Cohesion Policy 2014-2020
- To promote health mainstreaming in Structural Funds
- To ensure that patients perspective is fully integrated in Cohesion Policy from design to final evaluation
- To ensure that patients are recognised as a special target group
- To ensure access to funds to small NGOs
- To ensure that a patient voice is integrated in relevant monitoring committees
- ...
- ...

COHESION POLICY

Some general challenges

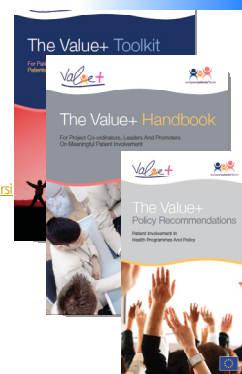
- Competition in Cohesion Policy is extremely high
 - > **Sectorial level:** competition between different eligible policy areas
 - > **Geographical level:** competition between different countries and regions (richer vs. poorer countries/regions, urban areas vs. rural areas, peripheral vs. central regions etc.)
 - > **Governance level:** competition between national and regional authorities and between regional and local authorities
 - > **Stakeholder level:** competition between stakeholders within the same policy area
- Need to cooperate with other stakeholders within and beyond health sector (e.g. other civil society organisations)
- Knowledge of Cohesion Policy is needed to participate

RESOURCES

Value+ Tools

Series of Tools:

- ▣ **TOOLKIT** to enable patients to become more involved in EU funded projects including research projects available also in FR, DE, BG, ES, LT: <http://www.eu-patient.eu/Documents/Projects/Valueplus/German%20Version%20of%20the%20Value+%20Toolkit.pdf>
- ▣ **HANDBOOK** for **project promoters** and **coordinator** to acquire more skills to enable them to facilitate in practice
- ▣ a series of **Policy Recommendations** looking at linking research project outcomes with patient – centred policy development



APP 4 : AGM BRUSSELS 2011 LIST OF ATTENDANCE

EFAPH MEMBER

Pierre BRISSOT	France	EFAPH	EFAPH Honorary Vice-president EFAPH Scientific Committee	
Barbara BUTZECK	Germany	EFAPH	EFAPH President HVD President	
Françoise COURTOIS	France	EFAPH	EFAPH General Secretary	
Stephane DE MAEGHT	Belgium	HBA	Medical Advisor	
Jean-Daniel KAHN	France	EFAPH	EFAPH Treasurer	
Levente KUN	Hungary	HBE	HBE Board member	Excused
Ann Mc GRATH	Ireland	IHA	IHA Board Member	
Margaret MULLET	Ireland	IHA	IHA President	
Brigitte PINEAU	France	FFAMH	FFAMH General Secretary	
Graça PORTO	Portugal	AHP	AHP Vice-president EFAPH Scientific Committee	
Jean RIALLAND	France	EFAPH	EFAPH Honorary Founder President	
John RYAN	Ireland	EFAPH	EFAPH Scientific Committee	Excused
Anne SAILLEZ	Belgium	HBA	HBA Treasurer	
Mayka SANCHEZ	Spain	AEH	AEH Board member EFAPH Scientific Committee	
Anne Sophie SNYERS	Belgium	HBA	HBA Administrative Secretariat	
Ketil TOSKA	Norway	EFAPH	EFAPH Vice-president NHF President	
Judit VARKONYI	Hungary	EFPAH	EFAPH Vice-president HBE President	Excused

INVITED

José Maria ALUSTIZA	Spain		Radiologist
Walter AZZORI	Belgium	EPF	European Patient Forum
Edouard BARDOU JACQUET		France	CHU RENNES - Hepatologist
Ann DOOLEY	Ireland / Belgium		HH – patient
Robert EVANS	United Kingdom	Haemochromatosis Society UK	Scientific Advisor
Gerda HORN	Switzerland	Schweizer Selbsthilfegruppe Haemochromatose	Chairwoman
Olivier LOREAL	France	INSERM	INSERM Director of research
John SEVERN			
Robert SORRILL	Italia	Associazione per lo Studio dell'Emocromatosi	Board member
Desley WHITE	United Kingdom	University of Plymouth	PhD research student
Jochen ZWERINA	Austria	Hanusch Hospital Vienna	Rheumatologist

APP 5 : FINANCIAL REPORT



GENERAL ASSEMBLY Financial Report

BRUSSELS

September 8th, 2011

EXPENSES/INCOME ACTUAL 12/31/10

EXPENSES		INCOME	
Office supplies	628.74	Grants	11 500.00
Insurances	209.47	Memberships	1 048.00
Legal fees	717.60	Financial income	81.07
Printed material - Comm.	4 655.73		
Ads	232.10		
Public relations	109.20	Deficit	2 597.50
Travel expenses	4 540.68		
Travel expenses Brussels	1 294.62		
Missions – Living expenses	2 258.26		
Mail and telecom	80.72		
Banking fees	379.45		
Memberships	120.00		
TOTAL EXPENSES	15 226.57	TOTAL INCOME	15 226.57



TREASURY ACTUAL 12/31/10

TREASURY as of 12/31/2010	8 319.23 €
Bank account	1 298.85 €
Savings account	7 000.00 €
Cash	20.38 €
+ INCOME	+ 35.18 €
- EXPENSES	- 1 330.66 €
Payables	1 847.82 €
Provisions	- 517.16 €
= TREASURY BALANCE 12/31/2010 :	+ 7 023.75 €

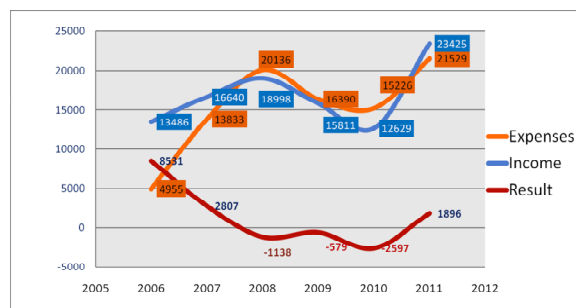


2011
ACTUAL + 4 MONTHS ESTIMATED

EXPENSES/INCOME FORECAST 12/31/11

EXPENSES		INCOME	
Office supplies	678	Services rendered	300
Insurances	101	Sponsors	10 000
Translation fee	322	Grants	11 515
"Public Institution" status	2 500	Memberships	1 520
Printed material - Comm.	173	Financial income	90
Ads	342		
Public relations	126		
Travel expenses	15 467		
Travel expenses Brussels	1 483		
Mail and telecom	124		
Banking fees	38		
Memberships	175		
TOTAL EXPENSES	21 529	TOTAL INCOME	23 425
Result : EXCEDENT	+ 1 896		
TOTAL	23 425	TOTAL	23 425

INCOME / EXPENSES EVOLUTION SINCE 2006



INCOME/EXPENSES EVOLUTION 2006-2011

Years	2 006	2 007	2 008	2009	2010	2011	TREASURY FORECAST 12/31/2011
Income	13 486	16 640	18 998	15 811	12 629	23 425	
Expenses	4 955	13 833	20 136	16 390	15 226	21 529	
Difference	8 531	2 807	-1 138	-579	-2 597	1 896	8 920



2012

2012 BUDGET - INCOME

Membership fees	1 500
Grants	17 500
• Novartis	5 000
• IGNA	1 500
• Others	11 000
Sponsors	14 000
• Website	1 000
• Administration service	1 000
• Evenemential*	8 000
• Other projects	4 000

* Concert, tombola ...

TOTAL INCOME = 33 000 €

2012 BUDGET - EXPENSES

Operating expenses : 22 000 €

- Office supplies 800
- Bank/Insurance... 200
- Comm. - Printed material 2 700
- Website 2 000
- Travels (Paris, Brussels...) 9 000
- AGM 5 000
- Mail/Telecom... 500
- Banking fees 300
- Administrative service 1 200
- Membership fees (EPF, ...) 250
- Financial expenses 50

Projects : 11 000 €

- Event 2 500
- Creation / support 5 500
- New EFAPH members
- Miscellaneous 3 000

TOTAL EXPENSES = 33 000 €

E.F.A.P.H

European Federation of Associations of Patients with Haemochromatosis (F.E.A.M.H : Fédération Européenne des Associations de Malades de l'Hémochromatose)

(Statutes in compliance with standard statutes as approved by the French Council of State,
Journal Officiel No. 1068)

I. Objectives and composition of the federating Association

Article 1:

The federating Association known as the “European Federation of Associations of Patients with Haemochromatosis”, hereafter designated as the EFAPH, was established on 11th September 2004. The EFAPH was created between those European Haemochromatosis Associations which adhere to the present statutes. Its aim is not only to federate all Associations concerned with Haemochromatosis through their practical initiatives (prevention, screening, training and informing members and the public at large), but also to heighten public awareness (notably amongst public services and authorities, as well as doctors) of the genetic Haemochromatosis condition. The EFAPH will exist for an unlimited period.

Its headquarters are located at 4, rue Paul Demange, Croissy-sur-Seine (78290), in the Yvelines département, France. The headquarters may be relocated by simple decision of the Board.

Article 2:

The EFAPH's means of action are practical field initiatives such as prevention, screening, training and informing members, the public at large, health professionals and the relevant authorities. To achieve this, the EFAPH assigns individuals and legal entities to represent its interests with various international, national and regional health authorities, public and private hospital, medical and administrative services, wherever its presence is required. It also informs all its members and the public at large, by any means at its disposal.

Article 3:

The EFAPH is composed of Associations legally registered with the regional or local authorities of their country of origin, or by duly appointed delegations, whose objectives are compatible with article 1 of the present Statutes.

The founding Associations are:

- A.H.O: Association Hémochromatose Ouest “Bretagne - Pays de Loire.”

- A.E.H: Asociacion Española de Hémocromatosis
- A.H.B: Association Hémochromatose Belgique

Requests for new membership are subject to the approval of the Board by vote, in compliance with article 1 of these Statutes. All member Associations must be certain their decision complies with their respective statutes, and must have obtained the consent either of their own Board or during their General Assembly.

Each member Association designates an officially appointed representative duly authorized to vote on its behalf. A deputy representative must also be appointed to ensure continuity if the official representative is unable to fulfil his or her function.

Each member Association will pay the annual dues decided by the previous General Assembly. Annual dues can be increased if the General Assembly so decides.

Honorary membership can be attributed by the Board to people for the signal services they render or have rendered to the EFAPH.

The Board can decide on a special derogation to article 1 of the present Statutes and accept individual membership.

Article 4:

An Association's membership can be terminated by:

- 1) Resignation, decided in accordance with the Statutes by the General Assembly or the Board; three months' notice is required previous to the end of the accounting year, currently at 31st December.
- 2) Dissolution of this member Association, or any substantial amendment of its statutes, resulting in the loss of compliance with article 1 of the EFAPH's Statutes.
- 3) Expulsion decided by the EFAPH's Board, pursuant to a member's repeated absences, non-payment of its dues, or for any other serious motive.

The member concerned is previously invited, by registered letter, to provide any explanations to the President of the EFAPH or to his or her duly mandated representative. These explanations will be submitted to the Board.

II. Administration and operations:

Article 5:

The EFAPH is administered by the Board comprised of the number of members decided by resolution at the General Assembly consisting of at least 3 members and at most 11 members amongst members of the EFAPH, except for individual members as defined under article 3.

Members of the Board are elected by secret ballot, for 3 years, by the General Assembly and chosen among the various member categories that comprise this Assembly.

In the case of a vacancy, the Board provides for the temporary replacement of its members, and the permanent replacement will be voted upon at the following General Assembly.

The authorities of members thus elected expire at the end of the replaced member's mandate.

Each administrator can only hold one mandate.

If the number of candidates is inferior or equal to the maximum authorised number of the Board members to be elected, excluding Honorary Founding Members, the General Assembly will then endorse the election of all candidates without having to proceed with a vote.

To elect Board members, each member of the EFAPH will indicate on its ballot paper, by order of preference, its choice amongst the candidate members. A number of points will be attributed to each candidate member according to their ranking on each ballot paper in compliance with the following rule:

- 1st place : N points
- 2nd place : N-1 points
- 3rd place : N-2 points
- Xth place : N - (x-1) points

“N”: number of candidates

At the end of the vote, and within the limit of the maximum number of members to be elected, the candidates who have obtained the most points are elected.

Honorary Members attend the Board Meetings, participate in the debates, but do not have the right to vote.

The Association's Honorary Founder Members are automatically members of the Board and dispose of the same rights as all other members of the Board.

The Board will elect, by a relative majority and among members of the Board, an Executive Committee comprising at least a President, if necessary one or several Vice-President(s), a Secretary-General, a Treasurer, as well as, when possible, a Deputy for each function who will ensure continuity in case of non-availability.

The Executive Committee is elected for one year.

Article 6:

The Board meets at least once a year, or whenever its President invites members of the Board to attend a meeting, or upon the request of a quarter of the EFAPH's members.

At least one third of the members of the Board are required to attend to validate decisions. In the event of a majority not being achieved, the President has the casting vote.

Minutes will be drawn up for each session. These minutes will be signed by the President and the Secretary. They will be drawn up on numbered pages, with no blanks or deletions, and kept at the EFAPH's Headquarters.

As the EFAPH's working language is English, minutes will be written in English and translated by members or their delegate into their respective languages for their internal communication.

Article 7:

The President of the Board, Vice-President(s), Secretary-General, Treasurer, or their deputies in the event of absence, constitute the Executive Committee. The Executive Committee implements decisions taken by the Board and handles day-to-day matters, proposes actions and projects and also prepares the Budget. The Executive Committee exercises all the Board's authorities and obligations, for which the Board has given it permanent delegation and for which it must report to the Board.

The Executive Committee meets at least twice a year, including at the statutory General Assembly, either physically or by any other means of communication (telephone conference or on line, videoconference, etc.). The presence of half of all members of the Executive Committee is required to validate its decisions.

Decisions are taken by majority voting of the Executive Committee members present or represented, and in the event of equal votes, the President has the casting vote.

Minutes of the meetings must be approved by the Executive Committee at the following meeting and signed by the President and Secretary. They will be drawn up on numbered pages with no blanks or deletions and are kept at the EFAPH's headquarters.

In the event of non-attendance to three consecutive meetings with no excuse provided, an Association's representative may be considered as having resigned.

Article 8:

Members of the Board will not receive remuneration for the functions they are entrusted with.

Only expenses will be reimbursed to all members of the Association (and/or their delegates) upon presentation of supporting justification and/or receipts. These reimbursements must be authorised by the President and/or the Treasurer and/or the Secretary once the request is submitted accompanied by the relevant receipts, which may be the object of verification.

Salaried persons paid by the Association can be called upon by the President to attend, on a consultative basis, the General Assembly and Board meetings.

Article 9:

The EFAPH's General Assembly is comprised of a duly appointed representative of each member Association, as stipulated by the statutes of each of the EFAPH's member Associations.

It meets once a year and is convened each time by the Board or upon the request of at least one quarter of the members of the EFAPH. Its agenda is established by the Board. It selects its committee which may be the Executive Committee.

It is informed of the annual report established by the Board, concerning the EFAPH's financial and legal status.

It approves the accounts for the past financial year, votes the budget for the following financial year, deliberates over questions on the agenda, and, if required, provides for the replacement of members of the Board. The accounting year corresponds to the calendar year, unless the Executive Committee proposes a change to the Board.

General Assembly meetings are not subject to confidentiality or secrecy and can be attended by guests and/or observers who may be invited by members who are up to date with their dues by the day on which the General Assembly is held.

In such circumstances, guests and/or observers have no right to vote, do not participate in voting on resolutions contained in the agenda, and can only express themselves publically when invited to do so by the designated Chairman of the meeting. Member Associations have two votes. Individual members have only one vote. Only members who are up to date with their dues on the day of the Assembly can vote.

Minutes will be drafted of the meetings. These minutes are signed by the Chairman and the Secretary designated for the meeting. They are drawn up on numbered pages with no blanks or deletions and are kept at the Association's headquarters.

Each member attending may only accept 2 proxies over and above his or her own vote. In the event of equal votes, the Chairman has the casting vote.

The annual report and accounts are provided to all members of the EFAPH each year.

Unless the measures stipulated in the previous article are applied, persons salaried by the EFAPH are not members and will not attend the General Assembly.

Article 10:

The President of EFAPH represents the Association in all civil matters. The President authorises expenditures. However, it is agreed that the President can delegate authorisation for expenditure to the Treasurer who will then inform the President and the Secretary-General.

In the event of legal representation, the President can only be replaced by a representative with special power of attorney.

The EFAPH's representatives must be in full possession of their civil rights.

Article 11:

Decisions taken by the Board concerning the acquisition, exchange and disposal of property required to meet the EFAPH's objectives, as well as mortgages for the aforementioned property, leases exceeding nine years, disposal of property contained in an endowment fund, as well as loans, must all be approved by the General Assembly.

Article 12:

Decisions by the Board to accept donations and legacies take effect in compliance with the conditions stipulated under article 910 of the French Civil Code.

Decisions taken by the General Assembly concerning the disposal of movables and real estate contained in an endowment fund, taking out mortgages and loans, must be validated by the Administrative authorities.

III. Annual resources

Article 13:

The annual funding of the Association is derived from:

- 1) Dues and subscriptions paid by its members;
- 2) Subsidies from the state, region, department, municipalities and public bodies/organisations;
- 3) Proceeds from gifts to be used as decided during the accounting year;
- 4) Financial resources exceptionally derived and, if required, with the assent of the authority concerned (collections, conferences, tombolas, raffles, concerts, dances and performances, patronage, donations, ...) authorised in aid of the EFAPH;
- 5) Financial resources derived from sales and payment for the provision of services.

Article 14:

Accounts will be kept showing an annual financial statement, balance sheet and appendix. Each of the EFAPH's branches must keep separate accounts which will figure in a specific chapter of the EFAPH's overall accounting records.

The use made of the funds resulting from subsidies granted during the past financial year are justified each year to the Head of the French Departmental Administration ("Préfet du Département"), Minister of the Interior and Minister of Health.

IV. Amendment of the Statutes and Dissolution

Article 15:

The Statutes may be amended by the General Assembly when proposed by the Board or by one tenth of the members who make up the General Assembly.

In either case, proposals to amend the Statutes will appear on the agenda of the next General Assembly, which must be sent to all members of the Assembly at least 15 days in advance.

At least a quarter of all active members must attend the Assembly. If this quorum is not obtained, a second General Assembly will be held, but not less than fifteen days later, and this time its decisions are considered valid, whatever the number of members present or represented.

In all events, the Statutes can only be amended by a two-thirds majority of the members present or represented.

Article 16:

If the General Assembly is specially convened to decide on the dissolution of the EFAPH, in compliance with the conditions stipulated in the previous article, this Assembly must be attended by at least half plus one of the active members.

If this quorum is not obtained, a second General Assembly will be held, but not less than fifteen days later, and this time its decisions are considered valid, whatever the number of members present or represented.

In all events, dissolution can only be decided by a two-thirds majority of the members present or represented.

Article 17:

If the EFAPH is dissolved, the General Assembly will appoint one or several audit commissioners for the liquidation of the Association's assets.

Net assets shall be given to one or more similar public or state-approved organisations, or to organisations mentioned under article 6, paragraph 5, of the revised French Associations Act of 1st July 1901.

Article 18:

The General Assembly's resolutions, as stipulated under articles 15, 16 and 17, are immediately sent to the French Minister of the Interior and to the Minister in charge of Health. They are only valid after receiving the Government's approval.

As the EFAPH's working language is English, The General Assembly's resolutions, as stipulated by articles 15, 16 and 17, will be sent to the French Minister of the Interior and Ministry in charge of Health after being translated into French.

V. Surveillance and Internal Rules

Article 19:

The President must inform, within three months, the French departmental or sub-departmental administrative centre of the district where the EFAPH has its headquarters, of any modifications concerning the Association's administration or management.

The EFAPH's ledgers, as well as its accounting records, will be presented on site whenever requisitioned by the French Minister of the Interior or the Departmental Head, directly to the aforementioned or to their delegate or any civil servant they may have accredited.

The annual report and accounts – including those of the local committees – are sent each year to the Head of the departmental administration, the Minister of the Interior and to the Minister in charge of Health.

The Secretary-General and the Vice-President(s) have permanent delegation from the President to act, as stipulated under the previous paragraphs of the present article.

Article 20:

The French Minister of the Interior and the Minister in charge of Health have the right to require their delegates to visit the branches created by the EFAPH and to receive reports on how they operate.

Article 21:

The Internal Rules are prepared by the Board and endorsed by the General Assembly before being sent to the Departmental administrative centre (Préfecture du département). They cannot come into effect, nor be amended, until they are approved by the French Minister of the Interior.

Statutes signed on _____, endorsed by the General Assembly held on _____

The President

The Secretary

Mrs. Barbara BUTZECK

Mrs. Françoise COURTOIS

APP 7 : MEMBERS OF EFAPH BOARD

I. Members of EFAPH BOARD (further to Brussels September 2011)

RIALLAND Jean, France, Founder and Honorary President

BRISSOT Pierre, MD-PhD, France, Founder and Honorary Vice-President

BUTZECK Barbara, MD, Germany

COURTOIS Françoise, MD, France.

EVANS Robert, MD-PhD, UK

KAHN Jean-Daniel, France

Mc GRATH Anne, Ireland

PORTO Graça, MD-PhD, Portugal

SAILLEZ Anne , Belgium

SANCHEZ Mayka, MD, Spain

TOSKA Ketil, Norway.

II. Members of the Executive Committee (elected by the BOARD) :

President : BUTZECK Barbara, Germany.

General Secretary : COURTOIS Françoise, France.

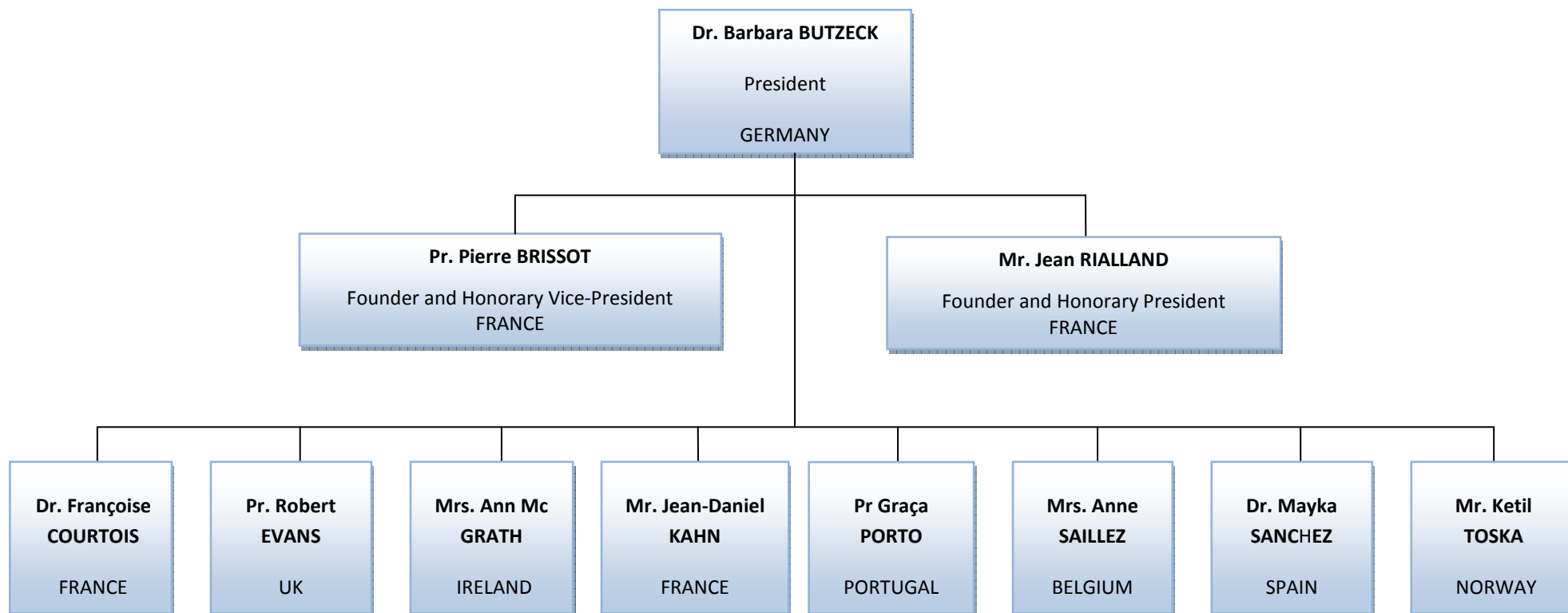
Treasurer and Deputy General Secretary : KAHN Jean-Daniel, France

Vice-President : SANCHEZ Mayka, Spain

Vice-President : TOSKA Ketil, Norway

APP 8 : ORGANIZATION CHART 2011

MEMBERS OF EFAPH BOARD (Further to Brussels 2011)



EXECUTIVE COMMITTEE

President : Dr. Barbara BUTZECK – Germany

General Secretary : Dr. Françoise COURTOIS - France

Treasurer and Deputy General Secretary : Mr. Jean-Daniel KHAN - France

Vice-President : Dr. Mayka SANCHEZ - Spain

Vice-President : Mr. Ketil TOSKA - Norway

Administrative service : Mrs Sophie SEGAUD - France

SCIENTIFIC COMMITTEE

Pr. Graça PORTO - IBMC Porto, Portugal (Chair)

Pr. Pierre BRISSOT - Pontchaillou University Hospital Rennes, France

Dr. Olivier LOREAL – Inserm U991 CHRU Pontchaillou, Rennes, France

Dr. John RYAN - Mater Misericordiae University Hospital Dublin, Ireland

Dr. Mayka SANCHEZ - IMPPC Barcelona, Spain

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