

MINUTES OF THE 9TH ANNUAL GENERAL ASSEMBLY London – April 19th 2013

Report : Françoise COURTOIS, Barbara BUTZECK, Jean-Daniel KAHN : May ????, 2013

Agenda : **Appendix 1**

In Attendance: BARDOU-JACQUET Edouard (France), BRISSOT Pierre (France), BUTZECK Barbara (Germany), COURTOIS Françoise (France), DE DECKER Tanguy (Belgium), DISTANTE Sonia (Norway), EVANS Robert (UK), FERNAU Janet (UK), KAHN Jean-Daniel (France), Mc GRATH Ann (Ireland), LOREAL Olivier (France), MULLETT Margaret (Ireland), PINEAU Brigitte (France), PORTO Graça (Portugal), SANCHEZ Mayka (Spain), SORRILL Robert (Italy), STAKVIK Dag Erling (Norway), TOSKA Ketil (Norway), VARKONYI Judith (Hungary)

Apologies :ALTES Albert (Spain), DE MAEGHT Stéphane (Belgium), HORN Gerda (Switzerland), RIALLAND Jean (France), RYAN John (Ireland), SAILLEZ Anne (Belgium), ZOLLER Heinz (Austria).

Invited : ANDERSON Greg (USA), BOMFORD Adrian (UK), DON Howard (UK), DON Eileen (UK), FARROW Kit, FERNAU Sarah (UK), GUGGENBUHL Pascal (France), HOWES Nicia (UK), KRIKLER Sam (Canada), Mc LAREN Gordon (USA), MARRIS Ben (Australia), MILMAN Nils (Denmark), SANTOS Paulo (Brazil), SINCLAIR Robert (South Africa), SWINKLES Dorine (Netherlands), TEIXEIRA Emerencia (Portugal).

Opening of the Annual General Meeting by the President **Barbara BUTZECK**. She expresses the satisfaction of all the attendants for having participated in the General Assembly of the International Alliance (IAHA) in the morning, during which most of the topics of general interest have been presented and discussed. Please refer to the specific IAHA minutes (separate document).

EFAPH has widely contributed to the officialization and consolidation of IAHA and welcomes this approach to widen the circle of HH centered organizations. The members of IAHA who have accepted the invitation to observe the EFAPH 2013 AGM are most welcome.

I. EFAPH Activity Report 2012-2013 : Dr Françoise Courtois , General Secretary (Appendix 2)

- Françoise Courtois (FC) summarized the activity of the Executive Committee during the period between the Rennes AGM (September, 2012) and now (ie. 7 months): 1 board meeting and 12 work sessions. She commented the main topics, details as per attachment.

- FC then reviewed the strong implication of EFAPH with Health organizations partners (EURORDIS, the European Hematology Association - EHA, European Patients Forum - EPF, Health First Europe - HFE).

- Of particular interest is the impulse from EURORDIS aiming at developing European Reference Networks (ERNs) for Rare Diseases. Further to the 6th EUCERD meeting (May 2012, Brussels) and to the 5th Conference of European Federations (October 2012, Paris) the preliminary work done by Graça Porto (Chair of EFAPH Scientific Committee) with the concept of Hironet has been consolidated and expanded into the **"RAGIODEN project"**. The current status is an application in the frame of the European COST 2012/2013, as developed by Olivier LOREAL in cooperation with the Scientific Committee and the member Associations. Please refer to the presentation in the IAHA Minutes (**Appendix 3**).

- FC has then given an overview of the new sponsors, as introduction to the financial report: Etablissement Français du Sang (EFS), the Ireland Fund of France, Eurordis, ...
- In the field of communication, the cooperation with YLB Conseil (Communication consultant) has continued by participating to the Celtic dinners, including some lobbying presentations by FC. A solid relationship has been established with the Irish Community in France which will culminate in a grant and communication actions.
- A particular highlight is the first issue of HemoNEWS aiming at widening the communication about HH to the general international public. At this stage two yearly issues are planned and the contributions from the member associations are warmly expected.
- Also, of particular interest has been the charity concert in Paris given by the famous international pianist Anne Queffelec and her son Gaspard Dehaene. Besides the artistic aspects the net return for EFAPH has been in the order of 10,000 €.
- Concerning the projects for 2013-2014, the emphasis is still on new members : Denmark, Austria (application letters expected).
- In addition to the Ragioden project (ERN), a project has been launched on clinical research about arthropathies (Barbara Butzeck, Pascal Guggenbuhl and the Scientific Committee).
- Last but not least, as a follow-up to the EP lunch debate, the progress is continuing on HH Observatories in Paris and the Ile de France region. It is hoped that more experiences will be launched in other member countries.

The activity report has been unanimously approved

II. Financial Report – Jean-Daniel KAHN, Treasurer (Appendix 4)

Jean-Daniel Kahn (JDK) has presented the Financial Report covering the fiscal year 2012 (12 months) as well as the 2013 Budget. He emphasizes that, concerning the resources, the situation is alike the one presented at the Rennes AGM (Sep.2012) : no recurring funding has been identified to replace the Novartis grant. Had it not been for the financial outcome of the Feb.2013 charity concert in Paris (please refer to FC's presentation) EFAPH could not cover the expenses corresponding to the current AGM.

The total 2012 **income** (table 2) has amounted to nearly 6,500 € , compared to more than 20,000 € in 2011. Worthwhile mentioning are:

- the 3,000€ grant from CARDIGEST (golf competition in Cissé-Blossac, Bretagne, France),
- the 1,200€ subsidy from EURORDIS for the organization of the 2012 AGM (unfortunately, in line with the policy of EURORDIS, this is a one-time subsidy which will not be renewed).

The total 2012 **expenses** (table 3) have amounted to nearly 7,000 €, compared to around 15,000 € in 2011. This reflects the care taken to minimize expenses, in view of the diminished revenues. The two highest expenses items are:

- Travel (incl. accommodation and living), over 5,000 €, corresponding to charges incurred for the Rennes 2012 AGM and some trips related to ExecCom meeting, to EFAPH representation and lobbying,
- Printing costs, app. 1,000 €, to support EFAPH's communication strategy.

The following table 4 recapitulates actual income and expenses. It shows a small "deficit" (450,- €) on the income side due to the accounting constraint for balancing the totals: it means that expenses have slightly exceeded the income.

The **treasury** (table5) at year-end 2012 amounted to more than 11,000 €, the bulk of it being placed in a savings account, as appropriate. The amount of 750 € shown as "expenses " corresponds to the downpayment accrued for renting Salle Cortot in view of the February 2013 charity concert. If one takes

into account the net revenue of this concert (in the order of 10,000 €, seats and gifts, minus the venue and piano rentals, minus miscellaneous items) one can consider that the Treasury balance of EFAPH was in the order of 20,000 €.

The 2013 **budget** should be considered provisory because there was not much visibility at the beginning of the year. It is a moderate and probably slightly optimistic projection. An update should be in order when the horizon will be clearer.

With respect to **expenses** (table 7) the budgeted total amounts to 13,000 €. The current London AGM amounts to 6,000 € (incl. one hotel night and 40 € IAHA gala-dinner participation for one representative per member Association); it is not shown on table 7 because it can be considered as already expensed. A 1,700 € envelope stands for the support (incl. travel) of at least one new national member Association in 2.013. The mention of Bulgaria is purely indicative (Austria and Denmark are also in the “starting blocks”). It is important that EFAPH participates (FC) in the EURORDIS AGM because the emphasis will be placed on ERNs and can result in fall-outs for the Ragioden project (not least EURORDIS support). A symbolical contribution (250 €) is budgeted by EFAPH for this strategical project. The other items budgeted are the usual ones (communication, lobbying, ExecCom and the related travel).

Concerning the budgeted **income** (table 8) it is (regrettably) quite simple. Besides the already mentioned outcome of the concert, EFAPH will receive a 1,500 € grant from the Irish Fund of France. No other resource can be budgeted at this time, which is quite worrying as it is likely to limit EFAPH capacities for action. This appears on the income/expenses evolution (table 9): for the second time since 2006 the expenses are exceeding the income.

JDK has pointed out, once more, that EFAPH is at this time in **structural deficit**. He urges once more the member Associations to change their state of mind and consider to creatively and actively participate in raising funds for the Federation which, as European “umbrella” acts for the common good.

The Financial report is approved unanimously

III. Renewal of the Board and the Executive Committee – period 2013/2015

On request of Barbara, Jean-Daniel KAHN confirms that, for reasons of personal convenience, he is not candidate to the Board and to the Executive Committee. A candidate is needed for the position of Treasurer. The audience is reminded that the elected members will exercise their mandate for 2 years and that, given the new statutes, the whole Board is subject to renewal (maximum 11 members). The Board then meets separately to elect the Executive Committee.

Elected Board members (unanimously):

Barbara BUTZECK (Germany)
Françoise COURTOIS (France)
Tanguy DE DECKER (Belgium)
Robert EVANS (UK)
Ann Mc GRATH (Ireland)
Graça PORTO (Portugal)
Mayka SANCHEZ (Spain)
Roert SORRILL (ITALY)
DAG Erling STAKVIK (Norway)
Ketil TOSKA (Norway)
Judit VARKONYI (Hungary)

Executive Committee :

President: Barbara BUTZECK
Secretary General: Françoise COURTOIS
Treasurer: Dag Erling STAKVIK
Vice President: Mayka SANCHEZ
Vice President: Ketil TOSKA

Barbara Butzeck welcomes Dag Erling Stakvik as new treasurer on the board. Jean-Daniel has accepted the request to serve as **Advisor** to the Board and to the Executive Committee (see organization chart, **Appendix 5**).

IV. Conclusion - Barbara Butzeck

Barbara concludes at the end of the AGM that besides the financial problems EFAPH could be very satisfied with its progress. The short presentation of the actions and hopes of the Dutch HH-Association by Dorine Swinkels, the attendance of Nils Milman from Denmark and the planned information meeting for HH- patients in Innsbruck, Austria at the end of June 2013 gives hope for three new EFAPH members applying soon. She thanks the HH Society UK for their contribution to the meeting by the numerous attendance of members and some grants. Regarding the HH-Arthropathy project she mentioned that she took the opportunity of the Biolron Meeting for contacting and interesting experts in different fields to collaborate. She thanks very warmly Robert Evans for his tremendous work for the organisation of the meeting and expresses her hope to welcome all members in 2014.

The preliminary date for the EFAPH General Meeting in 2014 is Septembre, 15th 2014. It takes place in Verona, Italy in the frame of the EIC congress, Septembre 11- 14th 2014.

Date: May 28th, 2013



Barbara BUTZECK
(EFAPH President)



Françoise COURTOIS
(EFAPH General Secretary)

Appendixes:

1. Agenda
2. Activity Report 2012-2013
3. Hemochromatosis European Reference Centers Network (Ragioden)
4. Financial Report
5. EFAPH Organization Chart 2013



IAHA and EFAPH members

“Yes, they can !” ...