

Paris, 8th of May 2007

**Summary of the European Workshop of Eurodis (European Rare Diseases  
Organisation)  
Paris – Pasteur Institute 4/5 May 2007**

**I. Overall Impression :**

It was an excellent forum for making contacts and sharing experiences. More than 300 representatives attended: the majority representing rare European diseases, members of the European Commission (responsible for health), pharmaceutical laboratories, members of research agencies (French & European)....

**II. Points of interest to EFAPH****1. EFAPH does not technically fit into the category of European Rare diseases:**

It was at the suggestion of Francois Houyes (Health Policy Officer with Eurodis) that we become an associate member as a first step to becoming more fully integrated as a full member . Two people work on the classifications of rare diseases: ORPHANET (Valerie Thibaudeau and Marie Georget) who will assist us under the guidance of Prof Brissot in preparing our line of argumentation for the rationale for considering iron metabolic diseases and not simply only the HFE gene when approaching the issue of classification).

**2. EFAPH is part of the extensive future work programme of Eurodis:**

- a. A strong link between the general public, clinicians and researchers (a privileged link made possible via Pierre Brissot and his position working with European researchers on iron metabolism projects)
- b. The creation of a European network (trans-relational): similar to the network consolidation and expansion that EFAPH itself is embarking on.

**3. In contrast however, EFAPH is in a more precarious position compared to the majority of other member associations of EURORDIS owing to the lack of necessary support from the pharmaceutical industry (research prospects, financial support etc.). EFAPH is unfortunately with very limited in this regard.****4. An interesting contact was made during the workshop : Susanna Leto di Priolo (Head of Oncology Department for Europe with Novartis) who offered a very interesting perspective of a multicentred European study of the physiological and psychological aspects of patients undergoing treatment for haemochromatosis. The aim of this study is to identify those that could benefit from chelation therapy. A contact will be in touch with a pilot group from EFAPH in September.**

**III. Other positiv points :**

1. A great development over the last 10 years is now the inclusion by DG Sanco (Department responsible for Health at the) European Commission to include EURODIS in all major policy decisions in the health sector for rare diseases (which is one of our major priorities, hence the need to quickly become a **full member**).
2. During the forum, we had the opportunity to come into contact with representatives from countries that are not currently members of EFAPH:
  - a. Bulgaria (Prof. Rumen Stefanov, Centre of associations of Rare Diseases in Bulgaria)
  - b. Romania (Viorica Cursaru)
  - c. Austria
  - d. Denmark (Elena Hulsman, Sigma Tau) and Prof Christian Gluud (Hepato-biliary group and ECRIN – an european network of infra structures for research).

These contacts, we hope will allow us to make contact with these local associations with the aim of inviting them to meet with EFAPH in London in September.

3. The European Union has recently called on proposals for scientific research under its seventh framework programme which provides funding for particular projects.
4. Finally, we have clearly seen the need for EFAPH to become involved in epidemiological studies re the prevalence of the HFE gene in European countries in order to get a better hearing with the officials at the European Commission.

**Finally :**

For EFAPH, outside of making immediate contact with these four european countries, it is foreseen:

- A workshop with Mrs. Parvanova, MEP (Health Spokesperson for the Alliance of Liberal Democrats in Europe), as a follow up to the EFAPH meeting with her held in April.
- A meeting with Françoise Grosstete MEP (Health Spokesperson for the European People's Party), who attended EURODIS meeting 4 May.
- A meeting with Mrs. Hildrun Sundseth (responsible for EU relations with cancer patient groups, planned for the next Brussels trip in May).

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