

Euro-Histio-Net Meeting, Frankfurt

Start: June 29, 1 p.m.

End: June 30, 2 p.m.

Participants: E Schaefer, J Donadieu, S Zafad, L Hessissen, M Girschikofsky, G Janka, R Haupt, I Astigarraga, R Price, J Haroche, I Malinowska

1: Overall evaluation of the EHN project.

The EHN project applied for European funding in May 2007 and officially started Sept 1st 2008. The funding period ended in August 2011.

The five objectives of the projects were :

1 To facilitate the access to information in LCH and associated syndromes

- For the patients and the families
- For the doctors

2 To increase the knowledge about epidemiology / risk factors / sequelae to determine better therapeutic measures by setting up an international database

3 To share expertise in difficult cases / meet the expert

4 To disseminate guidelines for the diagnostic work up, the therapy AND tissue banking

5 To stimulate the links between support associations

For 3 years, the budgeted overall costs were 555.000 €, the expected EU contribution 210.000€ split up as follows:

- 83 000 € for a project manager - Mrs Eva Schaefer (i.e. 25000 €/y)
- 72 000 € for IT (Web portal 30 000 €, Web data base 42 000€)
- 28 000 € for meetings and travels
- About 27 000 € for administration

The first objective was achieved and a multilingual website was opened.

The second objective was not achieved as no international data base has been opened during the time of the project. The main reason for this failure was the insufficient budget to find an IT company able to develop a web data base. The minimal offer for this DB was about 100 000 € while 42 000 € was available. However, the catalogue of data, and all the process of the constitution of a data base was launched. An agreement with the Histiocyte Society in order to make the HSDB available for data collection outside HS membership and clinical trials could not be realised. Thus, the budgeted sum of 42.000 € was not used.

Many parts of the third objective are achieved. Lists of frequently asked questions about LCH and rare diseases in general are available in many languages. Maps of experts for many European countries and contacts outside Europe have been elaborated. The technical facility of online expertise exists but most of the international exchange about difficult cases is done by email rather than by web or tel conference. This is in general a very difficult issue, even at national level, with regards to histiocytosis reality (i.e. a very multi systemic disease with a lot of competences requested at different times for a single patient). We can add that FAQ for HLH are ready in many languages.

The fourth objective was achieved but it remains a lot of work to do. Guidelines are written for childhood LCH (web site done / publication almost accepted), guidelines for adult LCH are finalised and approved but we know that this task requires constant updating.

The fifth objective is only partially achieved. The collaboration of EU patient associations for histiocytosis could not be enforced considerably, mostly due to restrictions of time. The language barrier is an important limitation to exchange as most of the members of national organisations communicate only in their respective native languages.

However, it is noteworthy that the continuation of the project, after the end of the EU support, is secured by support groups!

After final evaluation, the overall costs of the project were 428.000 €, the final EU contribution 170.000€. This is mainly due to the fact that no subcontractor for the web data base was appointed and the dedicated budget was not spent.

In addition to the evaluation of each objective of the project, a more global evaluation of the project was done:

The most negative point was the administrative burden. From the application to the final report, the administrative task represented about 40% of the time of the coordinator and of the project manager. The current rules for DG Sanco projects are extremely difficult to understand and they are applied whatever the size of the project. Several questions have to be emphasized. For example, it was considered that a patient association as an associated partner is a positive point in the management of a project, but the beneficiary work of members of non profit associations is not at all eligible for EU funding. Finally, the European Agency in charge in the evaluation of the project is focused on the administrative procedure. Specific conditions of the project are of little interest and a request for amendment of the grant agreement was not answered within 8 months (prolongation of the project of 2 months). At the end the only evaluation of the EAHC was financial and not at all scientific and it was an extremely rigid administrative process.

2: Expectations and organization for the next year

All participants agreed on the achievements of the project: the web site, the guidelines and the establishment of a relation between stakeholders which allow the continuation of the project.

All participants agreed that the EHN project is worth being continued and that its field of interest is not covered by other existing projects.

Dissemination of information towards professionals and towards the public is a public health task and the burden of the diseases is still important. We estimate about 600 – 1200 new cases per year in EU and a prevalence of about 4000 cases. Clinical trials are undoubtedly useful but in most of cases, the management of patients is conducted outside expert centres.

Present budget:

- Income about 18 000 €
 - 3 contributions only from patients associations
 - France 10 000 €
 - Germany 3 000 €
 - Belgium 5 000 €
- Expenses about 18 000 €
 - Part time project manager
 - 560€/month (1059 € including all ancillary wage costs)
 - Travel and meeting about 4000 €
 - Web site fee (about 40€)
 - No costs of administration – done by the French Study Group of Histiocytoses

3. New contents for the web site this year

There was a general agreement that further translations will be very helpful. The languages covered should address especially countries where no or few experts are known yet. The languages currently available on the EHN website cover more than 800 million native speakers worldwide. Arabic and Portuguese are now pursued and a main Chinese language will be a further language covering a large quantity of speakers.

Concerning the contents, the major aim of the next year will be to put the guidelines for adult LCH on the web and to encourage translators, because the situation of adult patients is even far more difficult in most of the countries. In addition, the contents about HLH and ECD shall be extended.

4. Histiocytopenia

There was a general agreement that the elaboration of an extensive histiocytopenia should not be a major aim for the next year. It will be difficult to make full texts available for patients. For doctors, the existing medical databases provide good facilities for literature research. The literature tool of the EHN website will therefore only be used to administer the references and bibliographies of the guidelines and other web contents.

5. Expert Sessions

The existing technical solution of the EHN website allows for uploading documents and sharing them with a group of invited physicians. It does not allow for screensharing and online conferencing. Different alternatives were presented and discussed. There was an agreement that there should be a solution in Europe, because data transfer to overseas is difficult. The EHN team will contact the Orphanet team in order to discuss the elaboration of a webconferencing tool for rare diseases in general. EHN will not be able to establish a solution with the existing funds.

6. How can we increase the link between patient support groups

It remains very difficult to strengthen the direct collaboration between European patient associations. This seems to be mainly due to restrictions of time and to a lack of availability of English speaking people. However, the patient associations are willing to financially support the project in order to keep it alive and to spread information as far as possible.

7: Future plans / perspectives

- All participants agree on the necessity to prolong the project for 2013 and beyond
- Support groups will be asked to provide the minimal budget to sustain EHN activity
- A new task will be to systematically explore the expertise of difficult cases by a web site. It is decided to explore the possibility of the St Jude system (www.cure4kids.org/ums/home/ and www.pond4kids.org/pond/home/) , the possibilities offered by orphanet and lastly by the present EHN system.

Final Conclusions:

Partners: As the project is not any more an EU funded project, we decided to abandon the terminology of associated partners and collaborative partners. All partners will be simply 'partners of the project'.

The list of partners is updated, and we have registered new partners in the south bank of the Mediterranean sea: Lebanon, Egypt and Morocco.

Project name: The name of the project will be changed from Euro Histio Net to Expert Histio Net
We will ask for the HON certificate

Webportal:

The field of diseases covered by the project will be:

- LCH
- ECD
- JXG
- HLH
- Rosai Dorfman
- SLC A29A3 (H syndrome or Faisalab)
- Histiocytic Sarcoma
- Other histiocytoses
- If possible differential diagnoses