

# Euro-Histio-Net Meeting, Boston

Held on October 17, 2010 5.30 p.m. – 7.30 p.m.

Hyatt Harborside Hotel at Boston's Logan International Airport

## Present:

- I. Astigarraga, Hospital de Cruces, Barakaldo, Spain (BIOEF)
- Elisabet Berglöf, Karolinska Institutet, Stockholm, Sweden
- J. Donadieu, Hôpital Trousseau, Paris, France (AP HP), Coordinator
- A. Filipovich, Histiocyte Society, Cincinnati Children's Hospital Medical Center, OH, USA
- S. Garcia-Obregon, Fundacion Vasca de Innovacion e Investigacion sanitarias (BIOEF)
- M. Girschikofsky, Austrian Working Group for Histiocytic Diseases in Adults, Austria
- R. Haupt, Istituto Giannina Gaslini, Genova, Italy (IGG)
- M. Maschan, Federal Research Center for Pediatric Hematology, Moscow, Russian Federation
- B. A. Miller, Histiocyte Society / Histiocytosis Association of America, Pitman, NJ, USA
- M. Minkov, St. Anna Children's Cancer Research Institute, Vienna, Austria (CCRI)
- D. Moustaka, Artemis Association, Greece
- V. Nanduri, Watford General Hospital, Watford, UK
- U. Poetschger, St. Anna Children's Hospital, Vienna, Austria (CCRI)
- C. Rodriguez-Galindo, Dana Farber Cancer Institute and Children's Hospital Boston, MA, USA
- J. Salotti, Newcastle University, UK
- J. Toughill, Histiocytosis Association of America, Pitman, NJ, USA
- S. Vaiselbuh, Cohen Children's Medical Center, New York, USA
- J. Visser, University Hospitals of Leicester, LRI Children's Hospital, Leicester, UK
- S. Weitzman, Hospital for Sick Children Toronto, Canada
- J. Whitlock, Hospital for Sick Children, Toronto, Canada
- E. Schaefer, Hôpital Trousseau, Paris, France (AP HP), Project Manager

## Opening of the meeting and welcome

Jean Donadieu, Chair, opened the meeting at 5.30 pm. and welcomed all attendees. After recalling the objectives of the project, he distributed a folder containing the agenda, three proposals for internet contact forms (general, for patients, for physicians) and a CD-ROM with 6 files:

- Digital versions of the three contact forms
- Dissemination Plan
- Dissemination Poster
- Translation Form
- Meeting Agenda and Presentation

## Adoption of the Agenda

The attendees adopted the meeting agenda without any changes.

### 1. Web Portal – Short presentation

SNTL Publishing GmbH & Co KG from Berlin, Germany, has been chosen as IT subcontractor for the Euro-Histio-Net web portal. The final version of the web portal is currently available under a confidential link. The functionalities already implemented were presented in the live version on internet.

#### a. Frequently Asked Questions.

- The system allows for category building.
- A slider functionality extends answers on demand in order to provide a clear structure.
- A keyword based administration shall be implemented within 3 months.
- If possible, a top FAQ functionality will be realised by the end of the project

#### b. Maps of Experts.

- The maps will be created by means of google maps.
- They will be embedded into the Euro-Histio-Net web portal.
- A first map (France) was created to show an example.

As soon as lists of centres are available for other countries, the maps will be created.

Following the discussions in the Bilbao meeting and the demonstration of the problem, how to define „expertise“ and on which base to choose the centres, Itziar Astigarraga's work group has analysed the current situation in Europe and the recommendations of the Rare Diseases Task Force (RDTF). After the presentation of the results of this analyse, the Euro-Histio-Net solution was suggested:

- For „Centres of Reference“, the RDTF definitions/recommendations for European Networks Centres of Reference (ENCR) will be strictly applied. Therefore, no ENCR for histiocytoses will be available for most of the European countries.
- For „Centres of Expertise“ or „Coordinating Centres“ in Langerhans Cell Histiocytosis, the Euro-Histio-Net work group has defined a minimum set of criteria:
  - Minimum number of patients seen
  - Participation in formal studies
  - Minimum number of peer reviewed publications
  - Being a member of the Histiocyte Society
  - Being a member of a national working group for LCH
- The Centres of Reference (if available) or the Centres of Expertise/Coordinating Centres shall compile lists of treatment centres / specialised centres for their countries.

These criteria were accepted by the meeting participants.

For the rarer histiocytoses, other criteria will have to be applied. For Erdheim Chester Disease, the ECD Global Alliance (one of the collaborating project partners) has suggested the following criteria:

- At least one peer reviewed paper on ECD (almost always a case study) OR
- Treated/seen multiple patients

One open question remains concerning additional categories which may be needed. Examples which will be analysed are:

- Centres for diagnostic confirmation (laboratories)
- Centres currently performing a clinical or epidemiological study
- Centres for special therapies (e.g. organ transplantations)
- Centres for follow-up regarding late effects, reactivations, and long term sequelae

The following activities are planned for the next months:

- All Histiocyte Society study groups in Europe will be contacted.
- All medical societies related to histiocytosis will be contacted.
- The local national coordinators shall be incorporated.
- The centres generated in national lists will be put in maps after permission of the concerned persons.

### c. Contact Forms.

There will be three different contact forms:

- The contact form for professionals will allow for presenting an outline of a special case (see Attachment 1).
- The contact form for patients will allow concerned persons to find some case related help (see Attachment 2).
- The general contact form will allow any other person to contact the Histio Net team with a question or a suggestion (see Attachment 3).

## **2. Web Portal - Approval of Contents**

The presented status quo of the webportal was approved by the attending project partners. The planned proceeding concerning FAQ, maps of experts and contact forms was agreed by the attending project partners.

## **3. Financial Report of Year 2 and Project Budget for Year 3**

60 % of the first pre-financing payment paid at the start of the project had been used up at the end of the first year of the project. 93% of the planned own contribution of the associated partners had been fulfilled. Therefore, the first further pre-financing payment after the first year of the project was paid without reduction. The second further pre-financing payment will be paid after the approval of the interim reports covering the period 01.09.2009 to 31.08.2010.

There may be some open budget resulting from the budget positions for the project management and for the IT solution of the web portal. The associated partners will discuss the use of this money. It could be used for an increase of the IT budget for the database, for a prolongation of the project until October 2010 (amendment of the grant agreement needed), or for a 4-6 years hosting contract with the IT company SNTL.

## 4. Guidelines

### a. Short Presentation.

Riccardo Haupt presented the main aspects of the guidelines for diagnosis, clinical work-up and treatment of Langerhans Cell Histiocytosis (LCH) and pointed out, which parts will be modified according to the suggestions of the involved experts:

- The document is a synthesis of similar documents already available: Histiocyte Society, France, United Kingdom, GPOH
- The contents were summarized and then edited, updated, reviewed, and discussed.
- It was decided to split up between children up to 18 years and adults. The presented document is dedicated to childhood LCH in patients not enrolled in studies or clinical trials. The contents are based on the best available evidence or expert opinion.
- It was decided to delete two of the four levels of certainty of LCH diagnosis and to keep only two levels: definitive diagnosis and presumptive (or compatible) diagnosis.
- It was suggested to delete the table listing the complete physical examination.
- The levels of agreement will have to be adapted after discussing the document in a larger group of experts.
- Two management algorithms show the different management of LCH according to site and extension of the disease.
- The paragraphe concerning single system LCH with skin lesions has to be modified and adapted to the newest evidence.
- There is a certain concern that the free availability of guidelines might jeopardize the enrolment rate into the protocol.
- The document contains recommendations for follow-up of LCH patients.

### b. Further Proceeding.

Riccardo Haupt will modify the first version of the guidelines according to the suggestions and will then send it again to the author's group.

## 5. Frequently Asked Questions about LCH.

### a. Short Presentation.

Itziar Astigarraga presented the main aspects of the FAQ lists:

- Many examples on the web have been reviewed.
- Questions and answers have been elaborated: There will be different chapters for LCH, HLH and rare histiocytoses, the lists will initially be simple and become more and more complex, and there will be different lists for patients and for physicians.
- A first version has been sent to the associated partners.
- The feed-back and suggestions will be reviewed.
- After the finalization of the lists, they can be translated.

### b. Further Proceeding.

The following activities are planned for the next months:

- A new version will be written based on the feed-back and suggestions of the associated partners.
- The new version will be sent to all project partners.
- Feed-back and suggestions will be welcome.
- Necessary changes will be incorporated.
- The contents will be put into the web portal.
- Translations will be done.

## 6. Data base.

### a. Status quo of the negotiations with AIT in Austria

The offer of AIT arrived at the end of July 2010. After having evaluated the offer, there are three major concerns:

- An amount of 7.125 EUR yearly costs for operation and maintenance: It will be difficult to secure these payments.
- It is obligatory to order at least 3 years of maintenance (2011-2013): The total amount of the offer will therefore be 50.000 EUR which exceeds the available budget of 42.000 EUR.
- The system will be built based on the LCH-CTP clinical trial system for the LCH IV database; structure and workflow must stay unchanged, form and field definitions might be updated: There is no reference to the complete catalogue of data defined for the Histio Net database.

### b. Further Proceeding.

The contract with AIT cannot be signed without further negotiations. The associated partners will try to negotiate more detailed descriptions.

## 7. Perspective after the end of the project.

Histio Net will make available scientifically approved information for many people worldwide: 508 million English native speakers, 417 million Spanish, 128 million French and 128 million German.

## 8. Arrangements for the Next Meeting.

In order to fulfill the tasks due in month 32 of the project, a meeting is planned in March 2011 and will probably take place in Genoa, Italy. It will be scheduled for two days, the first day starting at 11 a.m., the second day ending at 3 p.m.

If possible, funding for travel and hotel will be provided for those who cannot find other funding possibilities.

In August 2011 or October 2011 (if a prolongation of the project is possible), there will be a final meeting in order to finally approve all web portal contents and to finalize the plan for the future of the project.

## 9. Any other Business.

No other matters were discussed.

Jean Donadieu closed the meeting at 7.45 p.m.

These minutes arise from the project *Euro-Histio-Net 2008 - A reference network for Langerhans cell histiocytosis and associated syndromes in EU* which has received funding from the European Union, in the framework of the Public Health Programme. Sole responsibility for the content of this document lies with the authors. The Executive Agency is not responsible for any use that may be made of the information contained therein.



**Online Support – FOR PHYSICIANS**

Please choose from the following lists what is applicable for the case you want to present and enter your email address very carefully! The marked fields (\*) are mandatory.

\* Full name including titles:

\* Correct Email Address:

\* Institution:

\* City:

\* Your Country:

- Austria
- Belgium
- Canada
- France
- Germany
- Greece
- Italy
- Poland
- Spain
- Sweden
- The Netherlands
- United Kingdom
- United States of America
- Other: \_\_\_\_\_

\* Age of the patient:

- Adult
- Child (under 18 years old)

Organs involved:

- Bone
- Skin
- Lung
- Liver
- Spleen
- GI
- Hematology
- Pituitary
- CNS
- Soft tissues
- ENT
- Genital mucosis or anus
- Mouth
- Other organs involved: \_\_\_\_\_

\* Disease:

- Langerhans Cell Histiocytosis
- Erdheim Chester Disease
- Juvenile Xanthogranuloma
- Rosai Dorfman Disease
- Hemophagocytic Lymphohistiocytosis
- Other Histiocytosis: \_\_\_\_\_
- Other Disease: \_\_\_\_\_

Status of the disease:

- Currently treated active disease
- Not treated active disease
- Non-active disease
- In reactivation
- Other: \_\_\_\_\_

\* Please note here your exact request:

\*  I agree that my contact email is sent automatically to different Histio Net experts.

**Case Related Help – FOR PATIENTS**

Please choose from the following lists what is applicable for the case you want to present and enter your email address very carefully! The marked fields (\*) are mandatory.

\* Full Name:

\* Correct Email Address:

\* Your Country:

- Austria
- Belgium
- Canada
- France
- Germany
- Greece
- Italy
- Poland
- Spain
- Sweden
- The Netherlands
- United Kingdom
- United States of America
- Other: \_\_\_\_\_

\* I am looking for:

- Information material
- Expert
- Patient group
- Other: \_\_\_\_\_

Short message with additional information:

⏪⏩

\*  I agree that my contact email is sent automatically to specialised doctors.

\*  I agree that my contact email is sent automatically to a patient association.

Send

\* Disease:

- Langerhans Cell Histiocytosis
- Erdheim Chester Disease
- Juvenile Xanthogranuloma
- Rosai Dorfman Disease
- Hemophagocytic Lymphohistiocytosis
- Other Histiocytosis: \_\_\_\_\_
- Other Disease: \_\_\_\_\_

Symptoms:

- Bone
- Skin
- Lung
- Liver
- Spleen
- Other: \_\_\_\_\_

Status of the disease:

- Currently treated active disease
- Not treated active disease
- Non-active disease
- In reactivation
- Other: \_\_\_\_\_

## Attachment 3: General Contact Form

### GENERAL CONTACT FORM

#### Email

If you want to contact the Histio Net team, please send us a short message.

Complete Name

Correct Email Address

Your message:

Has the information in this webportal been helpful for you?

- Very helpful  
 Satisfying  
 Not helpful