

Euro-Histio-Net 2008 Meeting, Bilbao

Held on September 14, 2009 5.30 p.m. – 7.45 p.m.

at Euskalduna Conference Centre, Bilbao, Spain.

Present:

- I. Astigarraga, Hospital de Cruces, Barakaldo, Spain (BIOEF)
- J. Donadieu, Hôpital Trousseau, Paris, France (AP HP), Coordinator
- B. Fahrner, St. Anna Children's Hospital, Vienna, Austria (CCRI)
- 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)
- B. A. Miller, Histiocyte Society / Histiocytosis Association of America, Pitman, NJ, USA
- M. Minkov, St. Anna Children's Cancer Research Institute, Vienna, Austria (CCRI)
- R. Price, The Histiocytosis Research Trust, Sutton Coldfield, UK (HRT)
- M. J. Stefaniak, Pediatric University Hospital Lublin, Poland
- L. Vangeebergen, University Hospital Gasthuisberg, Leuven, Belgium
- S. Van Gool, University Hospital Gasthuisberg, Leuven, Belgium
- E. Schäfer, Hôpital Trousseau, Paris, France (AP HP), Project Manager

Observers:

- C. Harris, Histiocytosis Association of America, USA
- C. Toughill, Histiocytosis Association of America, USA

1. Opening of the meeting and welcome (Jean Donadieu)

Jean Donadieu, Chair, opened the meeting at 5.30 pm., welcomed all attendees, and distributed a folder containing the agenda, the project schedule, a tissue bank questionnaire, a consent form for publishing data on the web, and a list of required information for the Euro-Histio-Net web portal.

After recalling the objectives of the project and the distribution of the project partners in Europe, he mentioned the major aims of the meeting:

- Inform the partners about the achievements of the project concerning organization matters, the consortium agreement, the web portal and the web data base.
- Decide about the contents of the web portal.
- Ask all partners to contribute contents to the web portal.

2. Adoption of the Agenda

The attendees adopted the meeting agenda without any changes.

3. Procedural Matters

Introductory to the procedural matters, Jean Donadieu announced that the consortium agreement between the associated partners is signed without further modifications. The document specifies the responsibilities of the project partners and will be disseminated by the web portal.

a. Required Improvements concerning Project Organisation (Eva Schäfer).

It was commonly agreed to hold meetings of the steering committee (the 5 associated partners) following the advisory board meetings in order to come to valid decisions for future activities. Further improvements concerning the project organisation shall be attained by having telephone conferences on a regular basis.

b. Decision Making for Web Portal Contents (Eva Schäfer).

Decisions about contents which will be added to the web portal will be made following the regulations of the consortium agreement: The contents will be sent to all project partners by giving a delay for an answer. If no answer arrives within the delay, this will be considered as an agreement. The final decision is taken under consideration of the feedbacks by a majority vote (absolute majority) of the associated partners.

4. Review of the first year of the project (Eva Schäfer)

a. Status quo of the Work Packages:

▪ **Web Portal.**

- A preliminary version of a Euro-Histio-Net web site has been put online at www.eurohistio.net. It serves for disseminating information about the status of the project, for acquiring new partners, and for providing contact data.
- The technical specifications for the final Euro-Histio-Net web portal are available since June 1st, 2009.
- The call for at least three bids was launched, but only one offer has arrived. Since the final version of the web portal is not needed until the contents are produced within the different work packages, the following suggestion was made: The Euro-Histio-Net team will finalize the technical specifications for the meet-the-expert and the parents/ patients website. There will be quite a lot of overlaps concerning the functionalities and therefore a potential to economize costs. In addition, the overall sum for the call will be higher and therefore more attractive for bidders.

This suggestion was agreed by the attendees.

The preliminary Euro-Histio-Net website was live presented:

- It contains links to the following web pages:
 - http://ec.europa.eu/health/ph_threats/non_com/rare_diseases_en.htm (European rare diseases webpage)
 - <http://ec.europa.eu/eahc/> (Webpage of the Executive Agency for Health and Consumers)
- It provides "News" information.
- It gives general information about the Euro-Histio-Net project and its partners.
- It provides general information about histiocytosis as a rare disease.
- Concerning project activities, each work package and the planned languages are described and documents like minutes are made publicly available. The information will continuously be updated according to the progress of the project activities.
- A contact template is available.

a. Status quo of the Work Packages:

The technical specifications of the final Euro-Histio-Net web portal and of the Meet-the-expert website were illustrated by means of a powerpoint presentation:

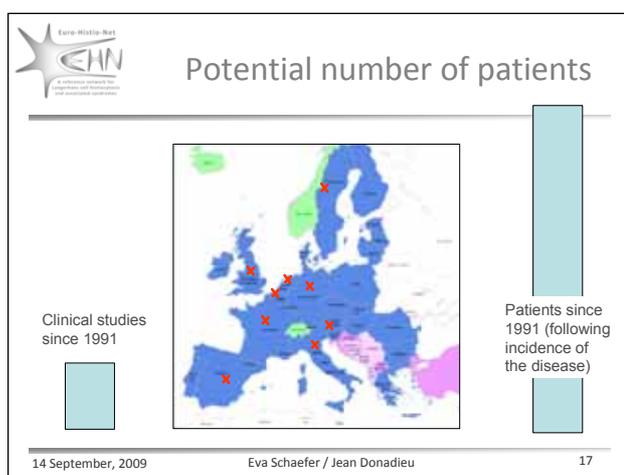
- Many web portal contents will be available in several languages. (Planned languages are Български, Deutsch, Ελληνικά, English, Español, Français, Italiano, Nederlands, Polski, Русский, Svenska – Bulgarian, German, Greek, English, Spanish, French, Italian, Dutch, Polish, Russian and Swedish.) A change between the languages shall be possible on each page of the portal in order to allow people to refer to other language versions if texts are not available in the selected language.
- The web portal will contain six main areas besides the pages “home” and “contact”:
 1. General information about the project, its partners, and rare diseases in EU.
 2. General information about Langerhans cell histiocytosis and associated syndromes (e.g. clinical presentation)
 3. Information about the web data base including a link to the website of the data base which will be a completely separate entity.
 4. Meet-the-expert website including several areas:
 - a. Frequently asked questions (FAQ) for public/patients
 - b. FAQ for professionals/doctors
 - c. Maps of centres of expertise in the EU and in the countries
 - d. Contact template / questionnaire for public/patients (after completing the form, the web portal shall automatically display a list of portal links; these links shall provide case related – i.e. questionnaire related – information)
 - e. Expertise of case (tool for online sessions / web conferencing for discussing difficult cases).
 5. Parents/Patients website providing information that is considered useful by patients (all international patient associations interested in contributing will jointly take the decision about the exact contents).
 6. Guidelines including diagnostic workup, therapy, follow up, and tissue banking.
- A slide illustrating the functionality and structure of the FAQ lists is shown in attachment 1. (It contains a dummy text without significance.)
- Slides illustrating the functionalities of the maps of centres of expertise are shown in attachment 2.

▪ **Web Data Base.**

- A preliminary agreement between the Histiocyte Society (HS) and the Euro-Histio-Net consortium (EHN) was signed. It mentions the following aspects:
 - Development of a single data base.
 - Technical specifications will be transparent and accessible for all.
 - Contract with subcontractors will be transparent and accessible.
 - Support of a large data collection: Mandatory data + clinical trials data + EHN data.
 - Subsidiarity: data controllers are not obliged to supply the whole catalogue of data.
 - Compliance with GCP.
 - Database guarantees to data controllers ownership and full responsibility for the use of the data.
 - Data specific to and directly pertaining to international clinical trial must not be published while the study is ongoing (concerning major endpoints, therapeutic arms, and data specified in the trials protocol).
 - Common database can be used without participation in an international clinical trial.
 - Data controllers have to ascertain the data quality.
 - Data controllers are responsible for the compliance with national regulations (e.g. patient consent).
 - HS and EHN will ensure that the software is safe and sustainable.

By the end of 2009, a contract between HS and EHN shall detail administration and use of the single data base.

- Planned construction of the data base:
 - o The HS data base does already include the mandatory data of EHN which was agreed upon December 19, 2008, and is listed in the EHN consortium agreement.
 - o The complete catalogue of data of EHN will be added to the HS data base as voluntary data. The catalogue will be agreed between the associated partners and negotiated with the Histiocyte Society in order to extend the HS data base.
 - o Worst case scenario: In case that any (e.g. legal) obstacles prevent a common data base, the HS data base will be “cloned” and for each patient who shall be included in both data bases (provided the informed consent), an automatic data transfer shall be possible.
- Possible scenarios for the use of the data base:
 - o Users who participate in clinical studies (e.g. LCH IV).
 - o Users who participate in different (clinical) studies and select from the catalogue all data they have to complete (following the study protocols) and they want to complete.
 - o User who don't want to participate in studies and select data from the catalogue (at least all mandatory data must be selected).
 - o Users who choose data from the catalogue and want to collect additional data. They can suggest an extension of the catalogue.



b. Intermediate Project Report.

The total amount of the project costs is 554.799 Euro, of which 209.314 Euro are funded by the EC. About 65 % of the first pre-financing payment (62.794 Euro) has been used. More than 50 % of the IT budget of 72.000 Euro will be used for the web data base, almost 25 % for the web portal and about 10 % each for the meet the expert and the patients' site.

5. Activity Plan for the second year of the project (Eva Schäfer)

a. Dissemination Plan.

A preliminary website was put online for granting dissemination, and the technical specifications of the web portal are finalized. The Euro-Histio-Net team has participated in meetings of 4 European patient associations. A handout for the Histiocyte Society meeting was prepared.

A dissemination plan is available and the dissemination actors are defined. The dissemination plan will secure dissemination on different levels:

- Among EU centers of reference of different countries
- Between non-specialized doctors and EU centers of reference
- Between patients/public/patient associations and European centers of reference

- Among the different patient associations
- Between patients/public and European patient associations

The dissemination plan will be sent to all project partners.

b. National Histiocytosis Networks.

The EU sponsored Euro-Histio-Net web portal will be used to inform public and professionals about the disease and available expertise. In each member state, the organisation of the care is different. The web site has to be 'factual' and will accept any personal position.

Some basic rules for the contents are:

- Cross border medicine is not recommended.
- Experts can request to be approved by any external authorities and be peer-validated.
- Potential criteria:
 - HS correspondents
 - Publication in the field
 - Agreement of a national pediatric society
 - Real contribution to EHN (translation..) and participation to any international study

c. Generation of Web Portal Contents.

- Meet-the-Expert Website (Itziar Astigarraga).

The work package "eMedicine – Meet the expert" has two major objectives:

- to provide web access to facilities for physicians to share expertise in difficult cases.
- to provide web access for patients and parents to a community forum and to information in multiple languages.

Access to lists of Frequently Asked Questions (FAQ) will be publicly available, whereas access to eMedicine sessions will be restricted by user profiles.

In 2009, the focus of the work package was put on the FAQ lists:

- The contents of many websites were reviewed.
- Questions and answers were elaborated, divided in different chapters for LCH, HLH and Rare Histiocytosis. The FAQ lists will initially be simple and will become more complex by continuously adding new questions. The BIOEF team will prepare these materials for the Euro-Histio-Net web portal.
- The FAQ lists are elaborated in collaboration with Susana Garcia-Obregon who is a biologist and not experienced in histiocytosis. She therefore can point out which questions are important to answer for non-experienced doctors and scientists.

The Spanish patient association against histiocytosis ACHE (Asociación Española contra la Histiocitosis, www.histiocitosis.org) has contributed a lot of knowledge concerning the use of web information, in particular their President Raul Suarez. The activities were supported by FEDER (Federación Española de Enfermedades Raras), the Spanish federation of rare diseases, and the private institution Inocente Inocente.

The ACHE web statistics for consultants counted 151.372 visitors in 2007. Only 6-7% of them were from Europe (Spain). The huge majority were visitors from America (USA, Mexico, Argentina, Chile, Colombia, Peru, Venezuela, and Brazil).

ACHE contributed knowledge concerning the following aspects:

- Concerns of the patients and families.
- Type of questions.
- Importance of a general formulary.
- General answers for FAQ.
- Personalized questions and answers: medical assistance.

Following the experience of ACHE, lists of reference clinical units, experts, hospitals, and pathologic units in the field of histiocytosis are needed.

On the occasion of the Histiocyte Society Meeting and the Euro-Histio-Net Meeting, the First National Day of Histiocytosis in Spain (I Día nacional de la Histiocitosis) was celebrated in Bilbao on September 15, 2009.

Itziar mentioned the following difficulties for realizing her work package:

1. The available budgets are very low: 3600 € for travel and 2.695 € for subsistence allowances for 3 years)
2. The whole amount of work is not funded but contributed by the Spanish project partner.
3. It must be defined, how exactly eMedicine sessions shall work and how access to information which is already exchanged between histiocytosis experts by mail can be expanded for other physicians.
4. For each web meeting, a responsible must be defined who organizes the meeting and it must be defined, if questions in real time shall be possible.

Summarizing the real conditions for the work package “eMedicine – Meet the expert”, Itziar pointed out that FAQ lists and Maps of experts / units can easily be provided. eMedicine sessions will perhaps only be possible for each country. If a tool for the exchange of diagnostic images is wanted, it must be defined who will review the images. Finally, it will be difficult to organize international internet meetings in real time due to time differences and daily work in the hospitals.

o Guidelines (Riccardo Haupt).

The work package “Guidelines in LCH and Tissue bank inventory” has the aim to provide access to:

1. Guidelines for LCH in children and adults for diagnosis, treatment, and follow-up.
2. Tissue banks inventory.
3. The endocrine follow-up web facility.

Therefore, topics to be addressed are the state of the art for LCH diagnosis in children and adults, treatment recommendations according to the disease extent (for front line and for reactivations), and guidelines for the follow-up and the assessment of late sequelae.

Following the request to all known histiocytosis experts to send any material which is available, four groups provided material:

- Histiocyte Society: Guidelines of Feb 2009
- UK group (Kevin Windebank)
- GPOH (in German)
- Austria/Germany (Michael Girschikofsky): Information about adult LCH

The Histiocyte Society Guidelines document contains 13 pages of treatment recommendations, based on LCH III results, plus protocol figures and bibliography:

- Diagnostic criteria: (morphology + immunophenotype)
- Surgical recommendations
- Pre treatment evaluation
 - History, Physical, Laboratory + imaging
 - Mandatory
 - Upon specific indications
- Definition of organ involvement
 - Risk organs, Special sites
- Clinical classification
- Treatment
 - Protocol if possible
 - “Standard treatment”
 - Front line (multisystem / multifocal bone, special sites, CNS)
 - Second line
 - Supportive care, Therapy modifications
 - Assessment of response
- Follow-up 1-5 years recommendations

The document of the UK group contains 7 pages, plus 2 tables and bibliography, and is written without using histiocytosis specific terminology:

- Classification of disorders
 - Antigen Presenting Cells
 - Phagocyte
 - Malignant disorders
- Epidemiology / etiology
- Clinical presentation
- Investigations at dx
- Treatment (summary of LCH I – II – III)

The GPOH document contains definitions (single/multisystem), symptoms, diagnostic criteria, and rationale for therapy. It is only available in German.

Concerning adult LCH, no guidelines exist. A review was published in a German journal and some presentations were given at the Histiocyte Society meeting in Cambridge, concerning lungs (Dr Fichter, Germany), therapy (Dr Doberauer, Germany), and diagnosis (Dr Girschikofsky, Austria). In addition, there should be some material of an adult meeting in London 2005 (J. Pritchard) which is not available yet.

Riccardo made the following proposals for the further proceeding:

- The Histiocyte Society shall be asked to send a request to all its members in order to get the complete available material from other groups.
- The text of the guidelines shall address different recipients (physicians and patients/parents). It therefore shall be differentiated.
- Finally, different types of answers shall be provided for the same question. Initially, there will be a priority to physicians.
- The used style shall be understandable also for people who are not specialized.
- Different working groups shall be created for childhood and adults.
- The following people shall be asked to participate in the working group for clinical presentation and work-up: J. Visser, M. Minkov, and R. Haupt
- The following people shall be asked to participate in the working group for treatment: M. Minkov and J. Donadieu
- The following people shall be asked to participate in the working group for follow-up: V. Nanduri and R. Haupt
- Other participants are very welcome. Please make suggestions.

- The first drafts should be realized before Easter 2010.

Concerning a tissue bank inventory, a questionnaire was sent to all teams involved in LCH research (see Attachment 3), asking for the following aspects:

- Existence of tissue bank
- Type of samples
- Storage conditions
- Ethical aspects
- Data on samples of associated malignancies will also be collected (LCH-Malignancy registry)

Only three answers arrived:

- France: 4 repositories (prospective)
 - 150 fixed tissue blocks
 - 120 DNA and cells (in UK!!! Geissmann)
 - 80 DNA in Geneton
 - 50 Adult LCH (St. Louis Hospital)
- Christine Delprat, France (she receives material from other groups, she doesn't store)
- Michael Girschikovsky, Austria (he doesn't store, but would be interested)

Therefore a second survey will be circulated and the introductory letter should perhaps be modified.

As regards the endocrine follow-up web facility, Riccardo pointed out the following aspects:

- The HS-approved long-term endocrine follow-up study will be accessible via the web site.
- Data will be securely protected and accessible only to registered participants.
- After demographic (e.g. age, sex) and clinical data (height, weight, Tanner stage), indication for further follow-up or laboratory testing will be provided.
- Link between web portal and main data base in Vienna.

o Patients/Parents Website (Eva Schäfer).

The second year of the project will be used to define the desired contents of this part of the web portal. This shall happen in collaboration with all interested patient associations. A questionnaire was sent to all international patient associations (see Attachment 4). Its first part aims at collecting important information about the contact persons and their availability for telephone and online conferences. The second part asks for the kind of information material for patients which is available in the associations. At the time of this meeting, no answers were available.

d. Future Prospects of Euro-Histio-Net (Jean Donadieu).

Several ideas exist concerning the future prospects for the use of the Euro-Histio-Net web data base, future projects, and additional project partners. Due to time reasons, these aspects were not presented in detail.

6. Discussion of Open Questions and Remarks.

No further questions and remarks appeared.

7. Final Conclusions – Allocation of Tasks.

The attendees agreed to proceed on the basis of the distributed list “Required Information for the Euro-Histio-Net web portal” (see Attachment 5). All project partners, except the patient associations, are kindly asked to provide the information requested in this document, referring to their own countries and considering the following hints:

1. List of officially declared centres of expertise: Officially declared centres of expertise do only exist in a few countries. They must have been declared by a public authority.
2. List of centres of experts: Centres of experts can be self-declared, but information about the basis of declaration must be provided.
3. List of FAQs you were asked by professionals. Please note questions without answering them.
4. List of categories and subcategories for the FAQs for professionals: Please provide an indexation you consider reasonable for an FAQ list for professionals.
5. National guidelines for histiocytosis or international guidelines accepted in your country: Please send the document to riccardohaupt@ospedale-gaslini.ge.it and describe the background of its creation and extend of acceptance in your country or tell Riccardo which guidelines are accepted in your country.
6. Tissue banks in your country: Please provide contact data of persons collecting tissues.

All project partners who did not attend the meeting are asked to complete the consent form for publishing data on the web (Attachment 6) and to send it to Eva Schaefer.

8. Arrangements for the Next Meeting.

The next Advisory Board Meeting will take place on the occasion of the Histiocyte Society Meeting 2010 in Boston, Massachusetts, USA.

The Steering Committee will have several telephone conferences and some online meetings during the next year 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.



Attachment 1: Illustration of the functionality of the FAQ lists



Euro-Histio-Net
A reference network for
Langerhans cell histiocytosis
and associated syndromes

Euro-Histio-Net – An international reference network for Langerhans cell histiocytosis and associated syndromes

Home

FAQ for Public

FAQ for Professionals

Centers of Expertise

Contact Professionals

Contact Patients

Expertise of Case

Euro-Histio-Net

Histiocytosis

Guidelines

Meet the Expert

Patients

Data base

Contact

Search by Category All Search by Keyword Search Tips Search

Top Frequently Asked Questions

1. **Bone:** Ein Fülltext sollte an bekannte Sprachen anlehnen, damit man sich mit ihm?
2. **Lung:** Kann jedoch sollte er möglichst wenig auf Teile einer tatsächlich?
3. **Multisystem:** Ein fiktiver Fülltext stellt inhaltlosen Text dar, statt den zukünftigen Scripten?
4. **Diagnosis:** Erst eingefügt werden soll. Dies ist gerade bei visuell-arbeitenden Scripten?
5. **Referent Centres:** Die von visuelle Variationen abhängig sind, ein wichtiges?
6. **Adult Histiocytosis:** Ein Fülltext sollte an bekannte Sprachen anlehnen? **NEW**
7. **Therapy:** Damit man sich mit ihm identifizieren kann, jedoch sollte er?
8. **Unifocal:** Einer tatsächlich existierenden Sprache verwenden. Ein fiktiver Fülltext stellt?
9. **Liver:** Text dar, statt den zukünftigen Text oder solchen, die von visuelle? **REVISED**
10. **Sequelae:** Visuell-arbeitenden Scripten oder solchen, die von visuelle Variationen?

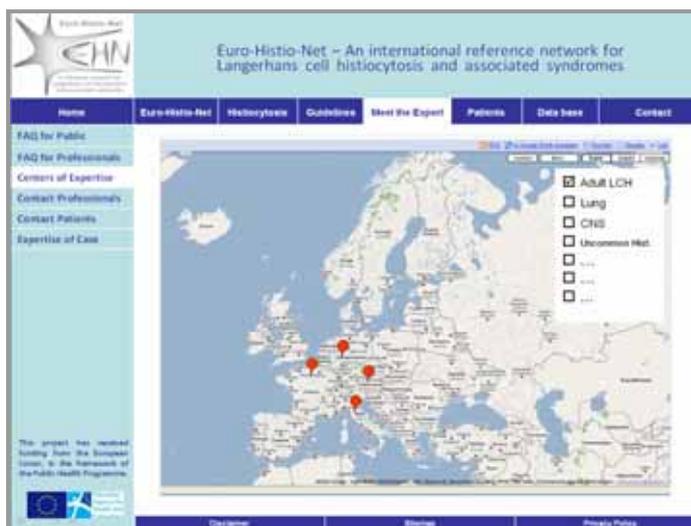
Table of Contents

- 1 Ein Fülltext sollte an More...
 - 1.1. Bekannte Sprachen anlehnen More...
 - 1.1.1. Damit man sich More...
 - 1.1.2. Mit ihm identifizieren More... **NEW**
 - 1.2 Kann, jedoch sollte er möglichst More...
- 2 Wenig auf Teile einer tatsächlich More...
 - 2.1 existierenden Sprache verwenden More...
 - 2.2 Ein fiktiver Fülltext stellt inhaltlosen More... **REVISED**
 - 2.3 Text dar, statt den zukünftigen Text More...
 - 2.3.1. Damit man sich More... **NEW**
 - 2.3.2. Mit ihm identifizieren More...

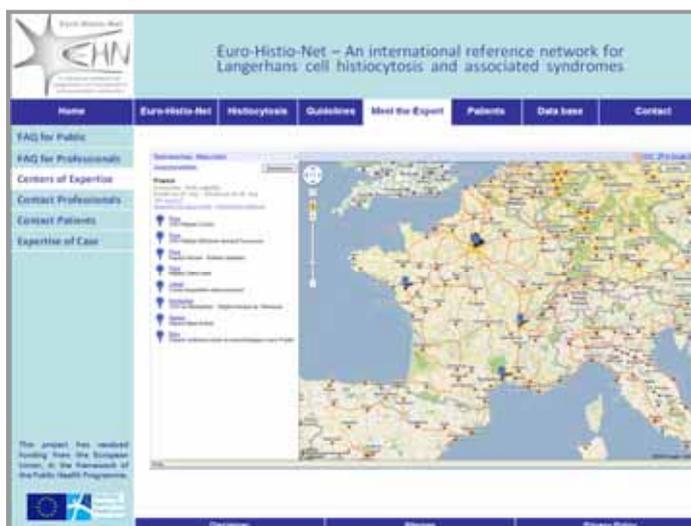
This project has received funding from the European Union, in the framework of the Public Health Programme.



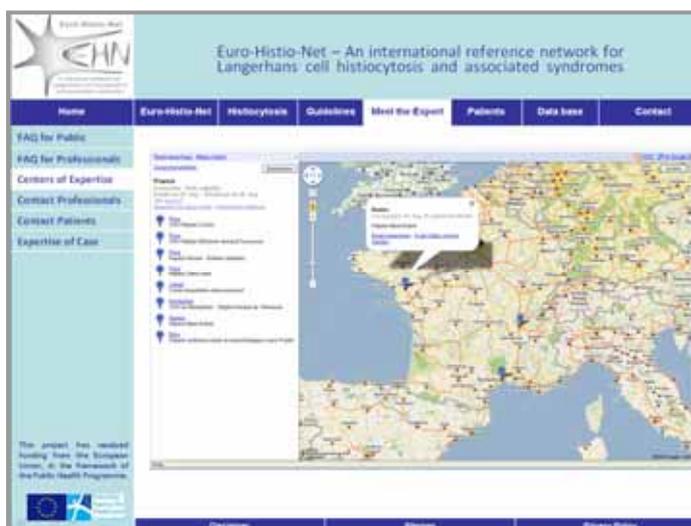
Attachment 2: Maps of Experts (illustrated by means of google maps)



A European map shall allow to choose rare specialties and to identify the location of the respective Centres of Expertise.



Maps of the European countries shall show the locations of the national Centres of Expertise including a short list with the names of the centres and their cities.



Preliminary information shall be shown for each Centre of Expertise, when it is chosen. The information shall contain links to further details about the centre and its specialties.

Attachment 3: Questionnaire for tissue banking

Euro Histio-Net

Euro Histio-Net

Survey on LCH tissue banks in Europe

Institution: _____

Town: _____ Country: _____

Person in charge: _____

1) Do you have a tissue bank in which you store material (blood or tissue) from patients with LCH?

No (go to question .):
Yes

2) If Yes, when did you start the Bank? (year) |_|_|_|_|_|_|_|

3) Do you store
any LCH case
only selected patients

4) At what time of disease course? (check all that apply)

Only at diagnosis:
At reactivation:
Not on regular basis:

5) What type of tissue do you usually store?

Tissue	Type		Temperature
<input type="checkbox"/> bone	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Skin	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Lymph nodes	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Blood (lymphocytes))	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Blood (serum))	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Other _____	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _
<input type="checkbox"/> Parents	<input type="checkbox"/> DNA <input type="checkbox"/> RNA	<input type="checkbox"/> In toto <input type="checkbox"/> Other: _____	_ _ _

Euro Histio-Net

6) Do you collect informed consent?

Yes always:

Yes since (year) YEAR

No: informed consent for enrolment in the clinical trial is inclusive of biobanking:

No:

7) Do you store also material from associate malignancies?

Yes:

No:

8) How many LCH patients do you have with at least 1 sample stored in your biobank?:

Notes: _____

Email: _____

Please send to:

Riccardo Haupt
Epidemiology and Biostatistica
Scientific Directorate
Gaslini Children Hospital
Largo G. Gaslini, 5
16147 Genova – Italy
e-mail: riccardohaupt@ospedale-gaslini.ge.it
fax: +39.010.3776590

Attachment 4: Questionnaire for patient associations



Please complete the following questionnaire in order to enable the Euro-Histio-Net team to organise the work for the patient/parent website. Your information will also be considered in the other work packages in order to ensure that the Euro-Histio-Net web portal becomes an effective international reference network.

A. Contact information and technical conditions

1. Your Association (* required fields):

Name of the association*:

Country/Region of operation:

Main language(s) of the association:

Main interests (HLH, LCH, all Histiocytoses, etc.):

Address:

Website:

E-mail address*:

Phone:

2. Contact details of the Representative for Euro-Histio-Net matters (* required fields):

Name*:

Function within the association:

E-mail address*:

Phone:

3. Skills of the Representative for Euro-Histio-Net matters:

Language skills:

IT skills:

Scientific/medical expertise:

Feasible commitment / Availability (hours per month):

4. Communication mechanisms & availability of representative :

Participation in European telephone conferences is possible (note that instructions for use will be provided)

Participation in online web conferences is possible (note that instructions for use will be provided)

Available times for telephone and online conferences:
 Working time (Mo-Fr, 8 a.m. to 5 p.m.) Evenings Saturdays Sundays

5. Should anybody else receive copies of e-mails concerning Euro-Histio-Net matters?

No

Yes, copy the following e-mail addresses -



B. Useful information for the Euro-Histio-Net project

1. Do you have Patient Information in Brochures or on the Web:

Yes, available now

→ Disease(s) -

→ Language(s) -

→ Last update (year) -

Not available

→ In preparation

→ Desired

→ Not interested

In your experience what are the most difficult issues in providing patient information?

2. Do you have a list of frequently asked questions (FAQ) for patients:

Yes, available now

→ Disease(s) -

→ Language(s) -

→ Last update (year) -

Not available

→ In preparation

→ Desired

→ Not interested

In your experience what are the most difficult issues in providing an FAQ list?

3. Availability of a web solution for patients' exchange (web forum, online chat, ...):

Yes, available now

→ Frequently used (>10 posted messages/month)

→ Regularly used (1-10 posted mess. / month)

→ Rarely used (< 1 posted message / month)

Not available

→ In preparation

→ Desired

→ Not interested

In your experience what are the most difficult issues in providing web-based patient forums?

4. Parent/Patient education and information concerning rare diseases and histiocytosis:

(Does your association have members who are skilled in educating new members and do they have opportunities to regularly update their knowledge?)

Skilled persons available

Regularly trained

Occasionally trained (< once per year)

Only self-trained

Not available

Regular training desirable

Exchange desirable

Not interested

In your experience what are the most difficult issues in the education of parents/patients?

Attachment 5: List of required information for the Euro-Histio-Net web portal

Required information for the Euro-Histio-Net web portal

1. List of officially declared centres of expertise
 - a. Name of the hospital/centre
 - b. If applicable, name of the specialised person
 - c. Area(s) of expertise
 - d. Declaring institution/organisation
 - e. Process of validation

2. List of centres of experts
 - a. Name of the hospital/centre
 - b. If applicable, name of the specialised person
 - c. Areas of specialisation
 - d. Declaring institution/organisation
 - e. Process of validation

3. List of FAQs you were asked by professionals.

4. List of categories and subcategories for the FAQs for professionals.

5. National guidelines for histiocytosis or international guidelines accepted in your country.

6. Tissue banks in your country.

Attachment 6: Consent form for publishing data on the web

Herewith I agree to the publication of the following data on the Euro-Histio-Net website www.eurohistio.net:

First and last name, Title: _____, _____

Email address: _____

Name of the hospital / the association: _____

Webpage of the hospital / the association: _____

Kind of partner: _____

Kind of contribution: _____

Date and Signature: _____