



Meeting 2013 in Paris, France

Start: November 22, 12 a.m.

End: November 23, 4 p.m.

Location: Cité Universitaire, Salon David Weill

Agenda

1. Welcome lunch and exchange between project partners
2. Short round of introductions and approval of new Histio Net partners
3. European Reference Networks (ERN)
 - Directive 2011/24/EU of the European parliament and of the council of 9 March 2011 on the application of patients' rights in cross-border healthcare: reinforcement of ERN for rare diseases
 - Procedures for identifying and designating ERN
 - Options for new histiocytosis projects
4. Round tables physicians' networks for LCH - situation in the different countries: Austria, Brazil, Egypt, France, Germany, Greece, Lebanon, Morocco, Netherlands, Poland, Italy, Spain, UK, USA (5-10 ' per country)
5. Round tables patients/parents associations - situation in the different countries
6. Histio Net project
 - Report 2009-2013: Short review of budget, scientific activities and achievements
 - Histio Net webportal: development of languages and statistics of visits
 - Histio Net newsletter and contact forms
 - Plan for 2014
7. Presentation of newly published webportal contents
 - Recommendations for adult Langerhans Cell Histiocytosis
 - Frequently asked questions about Erdheim Chester disease
 - Update of frequently asked questions about Hemophagocytic Lymphohisitocytosis
8. Histiocyte Society Meeting 2013
 - Reviews of symposia, scientific sessions and study protocols
 - Approval of information to update in the Histio Net webportal
9. Maps of Experts
 - Reference radiologists
 - Reference pathologists