



Meeting 2011 in Genoa

Start: March 11, 1 p.m.

End: March 12, 12 a.m.

hosted by Riccardo Haupt, Gaslini Institute, Genoa, Italy
(exact location will be announced)

Agenda

1. Final approval of the following web pages (ca. 1 hour)
 - Guidelines for diagnosis, clinical work-up and treatment of LCH during childhood (only concerning web presentation)
 - FAQ for patients and for professionals
 - Maps of Experts for Europe
 - Contact forms for patients and for professionals
2. Appointment of the following responsible persons and instructions for work (ca. 1 hour)
 - Translators or coordinators of the translation teams
 - Final approval before publication (one person for each language)
 - Compilation and final approval of national maps of experts (one person for each country)
3. Division of the following tasks and instructions for work (ca. 1,5 hours)
 - Authors for additional information on special aspects of LCH (e. g. genetics)
 - Authors for information about other histiocytic diseases
 - Translations
 - Dissemination of information about the web portal (one responsible patient representative and one responsible doctor for each country, if possible)
 - Compilation of link collections (one responsible patient representative for each country)
4. "Real life" (ca. 2,5 hours including discussions)
 - How can national and international expert teams benefit on the functionalities of expert sessions?
 - How can patient associations benefit on the web portal functionalities and strengthen international cooperations?
 - How will patients and doctors benefit on the Euro-Histio-Net web portal?
 - How will experts for rare aspects of LCH and for associated syndromes benefit on the web portal?
5. Data base (ca. 1,5 hours including discussions)
 - Presentation of the subcontractor
 - Future plans
6. Euro-Histio-Net after 2011 (ca. 1,5 hours including discussions)
 - Funding for a project manager in 2012 (almost achieved, but some contribution is still needed)
 - Prospects