



Meeting 2012 in Frankfurt

Start: June 29, 1 p.m.

End: June 30, 2 p.m.

(exact location will be announced)

Agenda

1. Welcome and short presentation of the current situation (ca. 30 min)
2. Euro histio net - a web site and more: expectations and organization for this year (ca. 1,5 hours)
 - Professional aspects
 - EU associations
3. New contents for the web site this year
 - a. Appointment of coordinating persons for translations to new languages (ca. 1,5 hours)
 - Use of translation forms
 - Use of the content management system of the webportal
 - Professional translations: how to find funding and qualified translators
 - b. Division of the following tasks (ca. 2 hours)
 - Authors for additional information on special aspects of LCH (e. g. genetics)
 - Authors for information about other histiocytic diseases
 - 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. Histiocytopenia (ca. 1,5 hours including discussion)
 - Literature tool of the webportal
 - Generation of literature lists
 - Provision of full text articles
 - Availability of full text articles (login secured?; for providers, for professionals, and/or for patients?)
5. Expert sessions - How to disseminate expertise (ca. 1 hour including discussion)
 - What is currently done
 - What can be organised
 - Possible benefit for patient associations
 - Possible benefit for histiocytosis experts
6. How can we increase the link between patient support groups (ca. 30 min)
7. Future plans (ca. 1,5 hours including discussion)
 - Application for a new grant
 - Alternatives