Histio Net – A Reference Network for the Creation of an International Web Portal for Langerhans Cell Histiocytosis and Associated Syndromes

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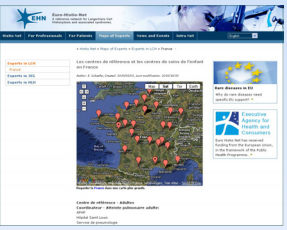
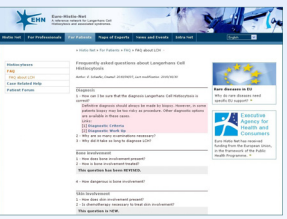
INTRODUCTION

A project for Langerhans cell histiocytosis and associated syndromes has received European funding and is supported by 30 project partners: physicians and representatives of patient associations involved in histiocytosis. Histiocytoses are very rare diseases affecting patients of all ages. Heterogeneous clinical presentations and unpredictable courses reach from involvement limited to skin or bone, with an excellent prognosis, to severe multisystem involvement associated with spontaneous poor outcome, requiring intensive cares. The heterogeneity of the disease necessitates a very particular competence from several medical specialists, whereas time and financial restrictions lead to difficulties in sharing acquired knowledge with patients and non-specialised treating physicians.

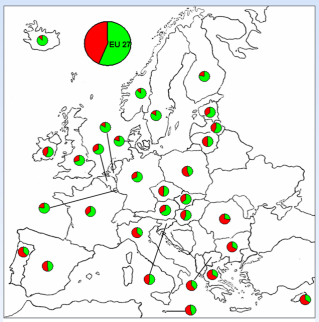


METHODOLOGY

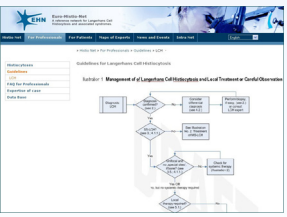
The project partners are associated physicians who have already a long commitment, both in the care of patients and in scientific work, and patients' associations. Based on their experience, the contents of four core work packages have been defined: medical guidelines and recommen-dations, online expert support, a web based data base, and a forum for patients' exchange. These elements will be accessible through the Histio Net web portal (www.eurohistio.net) as main dissemination instrument which will be a multilingual, secure, web-based portal. It will be an important contact point for everyone who is interested in LCH and associated syndromes. It will provide access to information, knowledge bases, and applications, for histiocytosis specialists, attending doctors, patients, and other people concerned with LCH and associated syndromes. The contents will be created in English and validated by the project partners. After this, they will be translated to many different languages. At present, translators for Arabic, Bulgarian, Dutch, French, German, Greek, Italian, Polish, Portuguese, Russian, Spanish, and Swedish have agreed to contribute.



The existence of the web portal will be published in many international medical societies, including pediatricians and general practitioners – as the first contact point for each patient – as well as specialists with regard to the numerous involvements: dermatologists, endocrinologists, ENT-specialists, hematologists, hepatologists, internists, neurologists, neuro-surgeons, oncologists, orthopedists, pneumologists, radiologists, and surgeons.



Percentage of persons (aged 16 to 74) using the internet on a regular basis in their private life (green). [Statistical Office of the European Communities, 2008].

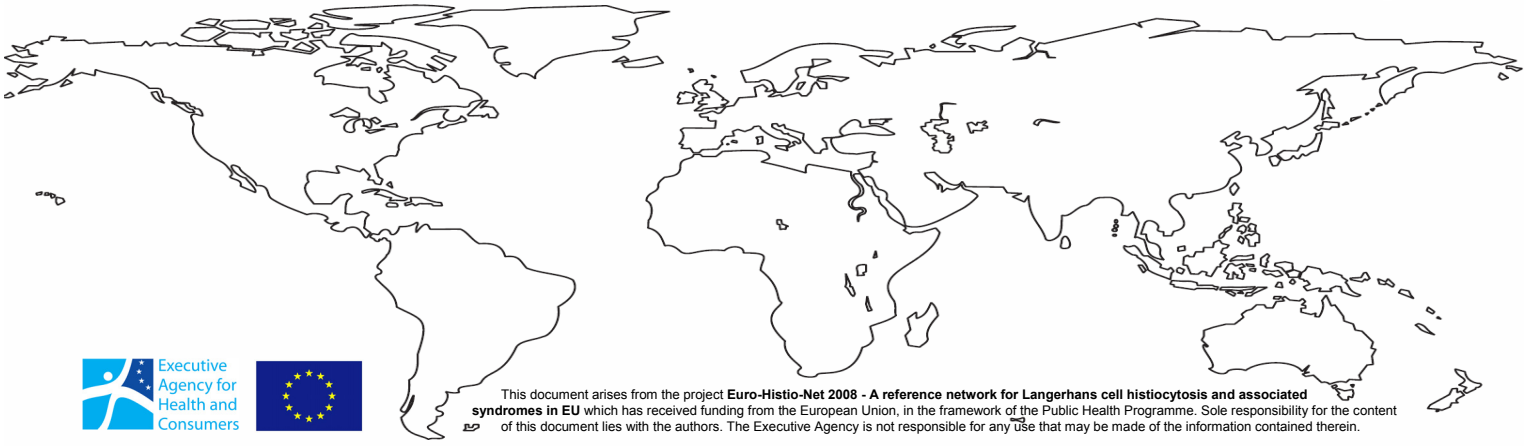


EXPECTED RESULTS

A common challenge in the field of rare diseases is the problem of knowledge acquisition and knowledge exchange. Histio Net wants to help solving this dilemma for LCH and related histiocytic syndromes. The web portal can improve quantity and quality of knowledge exchange and communication about histiocytoses at different levels: among centers of reference of the different countries, between non-specialized physicians and centers of reference, between patients and centers of reference, among the patient associations of the different countries, between patients and patient associations dealing in the patients' language.

CONCLUSION

The Histio Net web portal is intended to be an operative instrument of exchange for improving diagnosis, treatment, and follow-up of patients concerned by LCH and associated syndromes: www.eurohistio.net



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