



Euro Histio Net / Expert Histio Net - A Reference Network for Histiocytoses -

Eva Schaefer¹, Itziar Astigarraga², Riccardo Haupt³, Milen Minkov⁴, Richard Price⁵, Jean Donadieu¹

1 Hôpital Trousseau, Centre de référence des histiocytoses, AP-HP, Paris, France; 2 Hospital de Cruces, Barakaldo, Vizcaya, Spain; 3 Gaslini Children's Hospital, Genova, Italy; 4 St. Anna Kinderspital, St. Anna Childrens Cancer Research Institute, Vienna, Austria; 5 The Histiocytosis Research Trust, Sutton Coldfield, United Kingdom

Fig. 1: Guidelines for adult LCH are approved and included into the web portal. Logo will be removed after publication in a peer reviewed medical journal.

Fig. 2: The Arabic version of the Histo Net webportal is available since June 2012. FAQ about rare diseases are already available. Translations are ongoing.

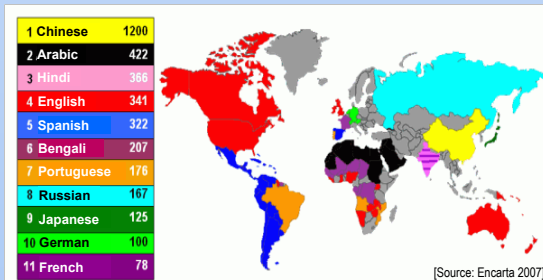


Fig. 3: New languages which will make histio net contents available to large groups of native speakers (in millions) are a main Chinese language, Portuguese, Russian, and Japanese. Voluntary translators are very welcome to contact histionet@web.de. Language tool incl. IT support (web publication of translated contents) is provided.

Histo Net partners - professionals: Jean Donadieu, France (coordinator); Eva Schaefer (project manager), Germany; Itziar Astigarraga, Spain; Robert J. Arceri, USA; Maurizio Arico, Italy; Michael Girschikofsky, Austria; Julien Haroche, France; Riccardo Haupt, Italy; Laila Hessissen, Morocco; Gritta Janka, Germany; Gregory Kaitas, Greece; Claudia Djambas Khayat, Lebanon; Polyzois Makras, Greece; Iwona Malinowska, Poland; Mariana Michalowski, Brasil; Milen Minkov, Austria; Vasanta Nanduri, UK; Carlos Rodriguez-Galindo, USA; Mariya Spasova, Bulgaria; Maria J. Stefaniak, Poland; Mohamed Sedki, Egypt; Stefaan Van Gool, Belgium; Johann Visser, UK; Sheila Weitzman, Canada; Saadia Zafad, Morocco

www.histio.net

BACKGROUND

Each year about 600-1000 children and adults in the European Union develop Langerhans Cell Histiocytosis (LCH) and associated syndromes. Diagnosis is sometimes difficult and once confirmed, patients and treating physicians have to look for scientifically approved information concerning adequate diagnosis, therapy and follow-up. The situation in many other countries worldwide is even far more difficult. The possibility to assess in native language is a key issue for many patients and even doctors in EU and beyond.

METHODS

30 international partners have contributed to create a secure multilingual webportal for histiocytosis specialists, attending doctors, patients, and other people concerned with LCH and associated syndromes. This project has received 3 years of European funding and is currently sponsored by 3 European patient associations: Histiocytose France, Histiocytose-Hilfe Germany and LCH Belgium.

RESULTS

The established webportal „Histo Net“ provides guidelines for childhood LCH, maps of experts for 9 countries, frequently asked questions about rare diseases in general, Langerhans cell histiocytosis, and hemophagocytic lymphohistiocytosis, and many links to international patient associations and study groups. Recommendations for adult LCH are approved and will be published soon. The technical tool for a keyword administrated literature database is available. At present, many contents are accessible in Arabic, English, German, Polish, French, Bulgarian, Italian and Spanish.

CONCLUSION

The Histo Net webportal is the first internet presence providing scientifically approved consensus based information about histiocytoses in many different languages. It is an important contact point for everyone worldwide who is concerned by or interested in Langerhans cell histiocytosis and associated syndromes. It provides the technical basis for additional languages in order to make information available in countries which are currently under-represented in the international group of histiocytosis experts.

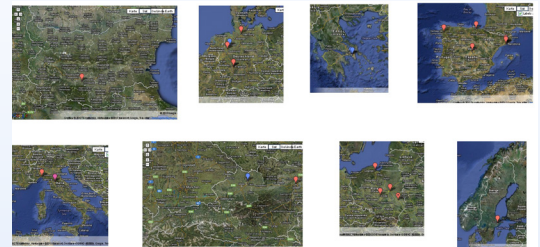


Fig. 4: Examples for maps of experts for Langerhans cell histiocytosis in different countries. Red: childhood LCH, blue: adult LCH, purple: both.

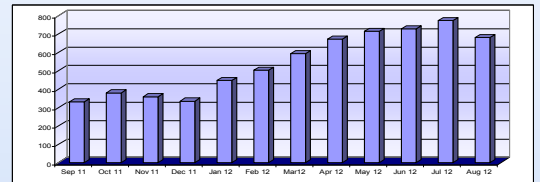


Fig. 5: Frequentation of the histio net webportal (visits per month). The average visit duration is more than 3 minutes (max. 58 min.) with an average of 4 visited pages per visit (max. 16 pages). 20% of the visitors access the webportal more than once. 2/3 of the visitors are referred to the webportal via search traffic and less than 10% use a mobile device (source: google analytics).

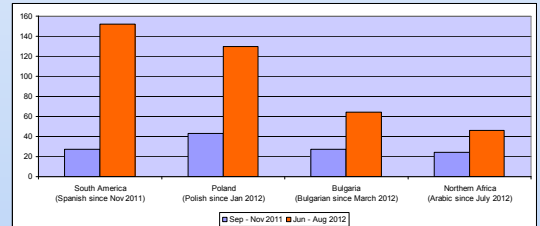


Fig. 6: Frequentation of translated histio net pages (visits in 3 months). Translation increases the frequentation considerably (source: google analytics).

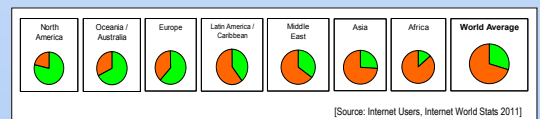


Fig. 7: Percentage of inhabitants using the internet on a regular basis (green).

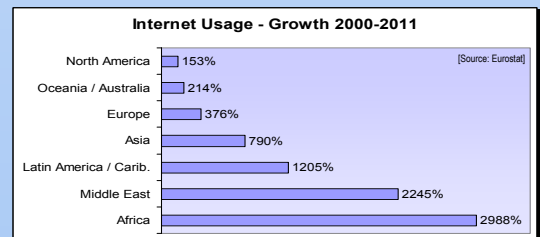


Fig. 8: The lower the percentage of inhabitants using the internet on a regular basis, the higher the growth of internet usage in the last decade.

Histo Net partners – patient associations: The Histiocytosis Research Trust, UK; Artemis Association on Histiocytoses, Greece; Asociacion Espanola contra la Histiocitosis de celulas de Langerhans (ACHE), Spain; Association Histiocytose France (A.H.F.); Associazione italiana ricerca istiocitosis (AIRI), Italy; Erwachsenen Histiocytose X e.V., Germany; Föräldraföreningen För Histiocytos (Ffh), Sweden; histiocytose nederland, The Netherlands; Histiocytosis Association, USA; Histiocytosehilfe e.V., Germany; LCH-Belgium; ECD Global Alliance, USA