

A Reference Network for the Creation of Online Expert Support for LCH and Associated Syndromes

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Fig. 1: The technical functionality for thirteen languages is available, additional languages can be added easily.

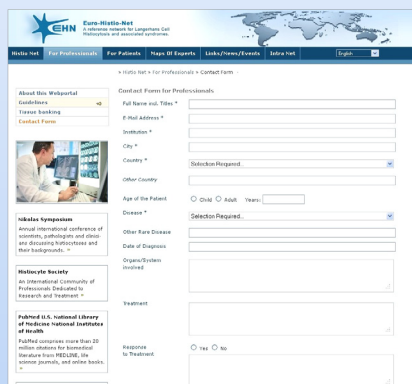


Fig. 2: Contact forms separated for professionals, patients and interested persons initiate automatic transfer to dedicated groups.



Fig. 3: Online expert sessions can easily be scheduled, prepared, held and archived - including a reference to a previous session. It is possible to upload files. After having scheduled the session, an invitation is sent to all members of the group, including all information and a link to the webpage. Online, comments can be added and a final summary can be drawn by the organizer.

www.histio.net

BACKGROUND

According to the incidence, known for children and estimated for adults, each year 1,400-2,500 children and adults in the European Union develop Langerhans Cell Histiocytosis (LCH) and associated syndromes. In several cases, patients have to wait many weeks, months or even years until diagnosis. Once confirmed, patients and treating physicians have to deal with histiocytosis, searching for scientifically approved information concerning adequate diagnosis, therapy and follow-up. The situation in many other countries worldwide is even far more difficult.

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 called Euro-Histio-Net has received European funding.

RESULTS

The project partners are 20 international physicians with high experience in LCH and associated syndromes in their respective countries and 10 international patient associations for histiocytosis. Based on their experience, the established webportal „Histio Net“ provides scientifically approved information about histiocytic diseases as well as about rare diseases in general. In combination with technical tools for online communication, the webportal is a „histiocytlopedia“ as well as an operative instrument of exchange. The core elements are medical guidelines, lists of frequently asked questions, separate for patients and for professionals, maps of experts, contact forms for patients and contact forms for case presentations and requests of professionals. Due to a sophisticated language administration, the contents can easily be translated. At present, 13 languages in three different alphabets are available.

CONCLUSION

The Histio Net webportal is the first internet presence providing information about histiocytoses in many different languages. It is expected to support histiocytosis specialists in their daily work and to enable patients and treating physicians to easily find scientifically established information. It therefore will be an important contact point for everyone worldwide who is concerned by or interested in Langerhans cell histiocytosis and associated syndromes.

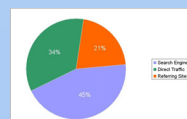


Fig. 7: Traffic sources overview

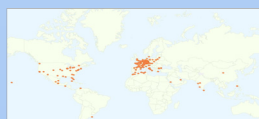


Fig. 8: Visitors came from four continents.

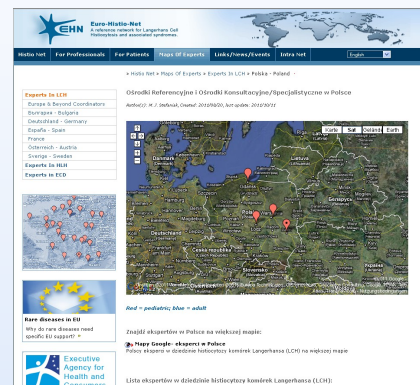


Fig. 4: Maps show experts in different European countries. The system is based on google maps and countries worldwide can easily be added.

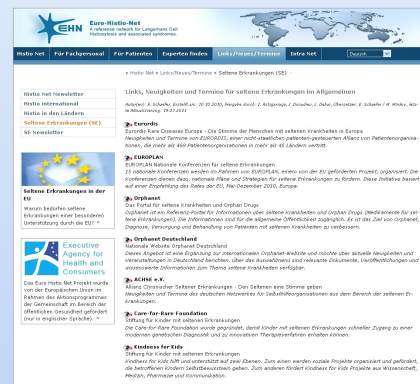


Fig. 5: Different web pages list national and international patient support associations for histiocytosis and for rare diseases in general.



Fig. 6: Web pages for kids explain the disease and the necessary examinations in words which children understand and show pictures with examples.