

TOWARDS A EUROPEAN REFERENCE NETWORK FOR GENODERMATOSES

First European Workshop on ERN recommendations and criteria in rare skin diseases.

5 October, 2013
22nd Congress of the European Academy of Dermatology and Venereology
Istanbul, Turkey

EXECUTIVE SUMMARY

Thanks to the European Academy of Dermatology and Venereology (EADV) support, 25 experts from 13 countries (Austria, Belgium, Croatia, Czech Republic, France, Germany, Hungary, Italy, Poland, Romania, Switzerland, The Netherlands, United Kingdom) and from two European and International patient networks (Debra International, European Network for Ichthyosis) met at the 22nd Congress of the EADV in Istanbul, on October 5, 2013.

The aim of this meeting was to discuss the development of a European Reference Network (ERN) for Genodermatoses.

First, speakers presented 3 European and International successful networks in the field of rare genetic skin diseases:

- the Genodermatoses Network of Fondation René Touraine (FRT), www.genodermatoses-network.org
- EB-Clinet, www.eb-clinet.org
- Geneskin, www.geneskin.org

Then, speakers presented strategies to develop a ERN for Genodermatoses, based on:

- the experience of the FRT Genodermatoses Network, www.genodermatoses-network.org
- the *Recommendations to the European Commission and Member States on European Reference Network for Rare Diseases* by the European Union Committee of Experts on Rare Diseases (EUCERD), www.eucerd.eu
- the perspective of EURORDIS, www.eurordis.org

Finally, the participants discussed on the 3 core components of an ERN for Genodermatoses:

- Diseases Registries, based on the experience of the International Dystrophic Epidermolysis Bullosa Patient Registry, www.deb-central.org
- Good practice guidelines and best standards of diagnosis and care, based on the experience of the German guidelines on ichthyosis
- Training and education tools based on the Geneskin experience

The European Reference Network for Genodermatoses initiative is coordinated by the Fondation René Touraine (FRT) Genodermatoses Network Committee (President: J. Bauer, President-Elect: C. Bodemer, L. Bruckner-Tuderman, A. Hovnanian, M. Jonkman, S. Karpati, I. Leigh, J. Mellerio, H. Traupe, G. Zambruno) in close collaboration with the EADV Genodermatoses Task Coordinators (H. Hintner and G. Zambruno).

A non-medical project manager works full time at FRT to deliver the actions for the development of the network.

To foster the development of the ERN for Genodermatoses, 9 subgroups led by 3 experts are being set up for each ERN core component. They are responsible for organising and developing the services for patients (please see the list of team leaders on pages 13-14)

Since 2013, the FRT Genodermatoses Network is co-funded by the EADV.

The next meeting with all the partners of the network should be held at the 11th EADV Spring Symposium in Belgrade, Serbia.

If you are interested in Genodermatoses, we need your expertise!
Please contact us at <office@genodermatoses-network.org>!