



Prof Johann Bauer

Genodermatoses Network

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Project proposer: Prof Johann Bauer

The project has 3 objectives:

1. To evaluate the needs of patients with genodermatoses and of their caregivers

To reach these aims the executive board of the project had monthly conference calls and face-to-face meetings on 5 September 2013, 21 November 2013, 20 March 2014, 18 July 2014 and 10 October 2014.

An international survey on medical and paramedical consultations for patients

with rare skin diseases was prepared in collaboration with EURORDIS and sent to patient groups. (To participate in the survey please contact office@genodermatoses-network.org.)

2. To strengthen links with genodermatoses experts and centres in the Mediterranean and Middle Eastern countries

To this end we organised training and networking sessions in Paris, France on 30-31 October 2014 and in Beirut, Lebanon on 6-7 November 2014 (60 participants from 15 countries).

3. To foster clinical and therapeutic research in the field of genodermatoses

To this end we identified a common list of first target diseases. Furthermore, we defined the structure of the future European Reference Networks (ERN) in collaboration with the European Commission representative and national public health authorities.

EADV support is of the utmost importance to further develop our project. This support is not only financial as it gives the project European recognition both at the scientific and the political level.

For further information, visit www.genodermatoses-network.org.