

Together Against Genodermatoses

N°1

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Since 2003, Genodermatoses in Mediterranean gets together stakeholders of the management of severe genodermatoses from Mediterranean and Middle-East countries. The aim of this project is to improve the health care and social care of patients with severe genodermatoses. This project has been initiated by Fondation Rene Touraine thanks to the support of one of its founding members: Laboratoires Pierre Fabre. Since 2008, this project is developing on the European level thanks to a co-funding from the European Union, in the framework of the Public Health Programme through the Together Against Genodermatoses grant (TAG n° 2007 335).

The 2009 working session, May 22-25, Greece

The *Together Against Genodermatoses 2009 working session*, the 6th *Genodermatoses in Mediterranean meeting* will be held in Greece, on May 22-25. The meeting is organized by the Hellenic Society of Dermatology and Venereology of Greece under the auspices of the Ministry of Health of Greece and Social Solidarity and the National Kapodistrian University of Athens, in the framework of the TAG project (TAG N° 2007 335) which has received funding from the European Union, in the framework of the Public Health Programme. Each

participant will present the following information: epidemiological data, progress in the assessment of needs of the patients and the costs for the patients, progress towards the development of centers of expertise, progress in the development of associations of patients, review of the strategies of the management of genodermatoses, development of a national network.

The 6 diseases working groups will meet: Epidermolysis bullosa group, Ichthyosis group, Palmoplantar keratoderma group,

Neurofibromatosis group,
Xeroderma Pigmentosum group,
Other genodermatoses group.

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The TAG Project: Improving Health Care and Social Support for Patients and Families with severe genodermatoses

Get together stakeholders at the European and international level

The general objective of the TAG project is to improve the delivery of health care and social support for patients and family affected by severe genodermatoses by getting together the stakeholders involved in the health care and the social support from the EU Member States and the candidate countries.

South Mediterranean and Middle-Eastern countries who have contributed a lot to genetic research and who have an extensive experience in the management of genodermatoses are involved as well.

Add value to public health programmes

The TAG project should contribute and add value to public health programmes by supporting the disease knowledge, the development of strategies and mechanisms for the exchange of information among people affected by rare diseases, the promotion of better epidemiological studies, the

European networks of reference for rare diseases.

Share experience and knowledge

To improve the delivery of health care and social support for patients and family affected by severe genodermatoses, partners will work together to

- identify and invite in 3 working sessions (2009, 2010, 2011) the main stakeholders of the health care and social support of patients with severe genodermatoses
- structure multidisciplinary and European working groups for the 6 groups of diseases
- exchange information on epidemiology, prevention, diagnosis and health care,
- structure national registries for epidemiology,
- participate in the definition of guidelines,
- list available resources/expertise,
- assess costs,
- discuss with pharmaceutical companies to improve access to drugs, cosmetics, medical devices
- support the development of community networks, of a network of centers of expertise and of a network of association of patients.

Genodermatoses in Mediterranean

Together for a better health care

Genodermatoses in Mediterranean - Together for a better care is an international



public health network, launched in 2003 by Fondation René Touraine in partnership with one of its founding members Laboratoires Pierre Fabre. This initiative is focused on patients and families suffering from severe genodermatoses in the countries of the Mediterranean basin and the Middle East.

This action is set up by dermatologists, dermatology and paediatric dermatology societies, public health officials, ministries of Health and Social Affairs, support associations, stakeholders of the management of the patients and their family.

MORE INFORMATION
www.genodermatoses-et-mediterranee.org