Together Against Genodermatoses

N°2

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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

Together Against Genodermatoses 2009, the 6th Genodermatoses in Mediterranean meeting

The meeting was held in Greece, on May 22-25 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.

Algeria, Croatia, Egypt, France, Greece, Italy, Libya, Morocco, Palestinian Territories, Portugal, Romania, Tunisia, Yemen, participated in the meeting. Cyprus and Slovenia sent their presentation.

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

The 6 diseases working groups met: Epidermolysis bullosa, Ichthyosis, Palmoplantar keratoderma, Neurofibromatosis, Xeroderma Pigmentosum, Other genodermatoses.

A new group was created, a transversal group: «Transsectional approach of genodermatoses for a preventive synergistic action»

Together Against Genodermatoses 2009

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2010 meeting

October 22-24

Rome, Italy

The 2010 meeting will be held in Italy, on October 22-24 at Ospedale Pediatrico Bambino Gesù.

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News from the countries

Egypt

Together for care of Genodermatoses in Egypt is a national public health network, launched in 2009.

This initiative is focused on patients and families suffering from severe Genodermatoses in Egypt.

Egypt has now a website dedicated to the health care and support of patients with genodermatoses in Egypt.

The partner organizations in this project are Kasr Alainy medical school, National Research Center (NRC) - Cairo, El-Haud El-Marsoud Hospital - Cairo, The Shark Al Medina Hospital - Alexandria, Ain Shams university-Faculty of medicine, Menia university-Faculty of medicine, Sohag university-Faculty of medicine, Assiut university-Faculty of medicine, Al Azhar University, Damietta faculty of medicine, Medical Research Institute - Alexandria, Alexandria University, Faculty of Medicine.
www.genodermatosis.eg.net

Genodermatoses in Egypt

www.genodermatosis.eg.net

News from the suport associations

Xeroderma Pigmentosum

Les enfants de la Lune : the documentary

On Tuesday, October 20, 2009 @ 20.35, France 5 TV broadcast a documentary: "Les enfants de Lune" (Xeroderma Pigementosum children).

Les enfants de la Lune : the French and Tunisian Associations

Enfants de la Lune (AXP) is the French support association for xeroderma pigmentosum. AXP was created in 2000 to inform and bring a moral and financial support to every family affected by Xeroderma Pigmentosum (XP). The association is member of Eurordis, Alliance Maladies Rares, Fédération des Maladies Orphelines. Its action covers mainly, France, EU Member Sates and Maghreb.

The Association d'aide aux enfants atteints de xeroderma pigmentosum (Support association for XP patients) was created in 2008 in Tunisia: *Through our action, we invite nous invitons XP patients and their parents to meet, to support each other, to share advice and information to manage this disease and overcome difficulties*, Noomen Hakim, President.

Les enfants de la Lune documentary

Synopsis

Lina is 12 years old. She lives in a small town, one hour from Tunis. She suffers from Xeroderma Pigementosum, also called the "moon children disease". In August 2008, the French

Association "Les enfants de la Lune" invited her with her mother to participate, for a week, in a camp organized for XP children and their parents. Meanwile, Mr. Hakim is creating a patient association.

MORE INFORMATION

http://wiki.france5.fr/index.php/LES_ENFANTS_DE_LA_LUNE

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