Together Against Genodermatoses

N°3

Newsletter 3 - December 2009

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).

News from countries

Kuwait

As is the experience with other Mediterranean countries, genodermatoses are prevalent in Kuwait. They are a cause of great concern to the families and most of them carry a great morbidity.

In order to have a better understanding of the extent of problem related to these disorders, a Genodermatoses Clinic was started in the Pediatric Dermatology Unit of As'ad Al-hamad Dermatology Center, Al-sabah Hospital in January 2000.

In this clinic, we provide tertiary care services to the Genodermatoses patients referred to us from all over the Kuwait. A registry of all the Genodermatoses patients referred to us is maintained.

Our primary aim is to provide the accurate diagnosis, appropriate available management and genetic counseling to these patients.

In addition to services provided by the ministry of Health, we also have an extended support from the Faculty of Medicine, Kuwait University, Faculty of Allied Health, and Kuwait Genetic Center for settling the diagnosis with their available resources.

For establishing the molecular diagnosis, we have been collaborating with various International Genetic/Dermatology Centers.

Epidermolysis bullosa and ichthyosis are the most prevalent genodermatoses registered with us.

From Arti Nanda, MD, DNBE, Consultant Dermatologist, Head of Unit, Pediatric Dermatology,, As'ad Al-Hamad Dermatology Center, Al-Sabah Hospital Kuwait.

Together Against Genodermatoses

2010

The 2010 meeting will be held in Rome, on 22-24 October 2010, in Ospedale Pediatrico Bambino Gesù, in the framework of the TAG project.

The TAG project (TAG N° 2007 335) has received funding from the European Union, in the framework of the Public Health Programme.

News from countries

Genodermatoses in Spain: more support required

Genodermatoses are as frequent in Spain as in anywhere else, but genetic testing is not widely available throughout the country. Although private laboratories are starting to offer genetic testing, the Spanish Public Health system is reluctant to pay the expenses involved and not all patients can afford it.

Consequently, some doctors ask for help from national or international research labs to confirm the suspected diagnosis genetically.

A National Registry of Rare Diseases was created in 2005 by the Public Health Ministry in order to collect clinical and epidemiological data from individuals suffering from infrequent diseases, a group which most genodermatosis belong to. The Carlos III Institute is the public institution responsible for this project, and all different registries of rare diseases can be found on its website (http://registroraras.isciii.es). Patients are strongly recommended to join these registries when available, as it is in the case of hereditary epidermolysis bullosa. However, as of today, keratinization disorders, xeroderma pigmentosum or neurofibromatosis do not have their own national registry.

Patients associations are working hard in Spain to provide access to information and social support to the affected patients and their families. Their number is on the rise, and they are getting more and more active trying to become known by society and patients. So far, patients with hereditary epidermolysis bullosa, ichthyosis, neurofibromatosis and hypohidrotic ectodermal dysplasia can benefit from their own association. I am happy to join the Mediterranean Genodermatoses group. We have a long way ahead to make this project grow.

From Dr. Angela Hernández-Martin, a staff pediatric dermatologist at the Niño Jesus´ University Children´s Hospital in Madrid. As a national reference centre, her hospital receives pediatric patients from all over the country. She has a great interest in keratinization disorders and hereditary epidermolysis bullosa.

News from the associations of patients

Eurordis

The European Organisation for Rare Diseases, EURORDIS, is a patient-driven alliance of patient organisations and individuals active in the field of rare diseases.

Eurordis' mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives.

The Voice of 12,000 patients

The Voice of 12,000 patients present patients' experiences and expectations regarding access to diagnosis and to health services, for a variety of significantly relevant rare diseases across Europe.

A chapter is dedicated to Epidermolysis Bullosa (p.143). DEBRA Croatia, partner of the Genodermatoses in Mediterranean and TAG project is on the EB patients contributing organisation to the The Voice of 12,000 patients. You can download this chapter on the Eurordis' website, as well as the results by other diseases and by country.

News from the associations of patients

Xeroderma Pigmentosum

A blog has been designed for *Les Enfants de la Lune* documentary . *Les Enfants de la Lune* is a 52 minutes documentary made by Feriel Ben Mahmoud et Nicolas Daniel in 2008, broadcast for the 1st time in France in October 2009 on France 5.
This blog is dedicated to prolong the documentary and bring more information about Xeroderma Pigmentosum.
Blog of the documentary Enfants de la Lune (French Support Association)

Association d'aide aux enfants atteints de xeroderma pigmentosum (Tunisian Support Association)

News from the working groups

Working Group	Coordinators
Epidermolysis Bullosa	M. El-Hachem (Italy) M. El Hashme (Libya)
Ichtyosis	C. Bodemer (France) M. Kharfi (Tunisia)
Neurofibromatosis	M. Bozghia (Libya) P. Wolkenstein (France)
Palmoplantar Keratoderma	N. Doss (Tunisia) A. Katsarou (Greece) B. Vosinioty (Greece)
Xeroderma Pigmentosum	M. Zghal (Tunisia) F. Seris (France) I. Benkaidali (Algeria)
Other Genodermatoses	C. Bodemer (France) H. Turki (Tunisia)
Transversal Group	S. Hadj-Rabia (France) Ghada El-Kamah (Egypt)

Working groups website

This new tool is developed thanks to Orphanet.

This private website is dedicated to the discussion between the participants in the working groups to issue recommendations to improve health care and social support for patients and families suffering from severe genodermatoses.

The goal of the groups is also to discuss the organization of a laboratories network dedicated to help patients and famillies while developing antenatal diagnosis.

Thanks to orphanet

a new webiste dedicated to the exchange of information between the participants in tne working groups

Executive Agency for Health and Consumers

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