



TOGETHER AGAINST  
GENODERMATOSES

2011



## Together Against Genodermatoses

13-14-15 October 2011

Hôpital Necker, Paris

Preliminary programme

### 13 October

A satellite professional training course open to everybody and especially to the younger teams - specialists and paramedics - willing to learn more about health care of patients with inherited epidermolysis bullosa and ichthyosis as well as genetic counselling and therapeutic education. Training will be in English and French (simultaneous translation). Grants will be awarded to younger teams responsible for genodermatoses consultations. The rules for grant applications will be sent very soon.

8.00 Registration - Coffee and croissants

#### Inherited epidermolysis bullosa

- 8.30 Classification, diagnosis procedure, *dermatologist*
- 8.50 Dressings, baths, antiseptics, analgesics, *dermatologist*
- 9.10 Nursing care gestures, *nurse*
- 9.30 Everyday life tips: *ergotherapy, physiotherapy, nurse, social worker*
- 10.00 Hand surgery, *plastic-surgeon*
- 10.20 Oral care, *dentist*
- 10.40 Nutrition difficulties, *nutritionist*
- 11.00 The partnership «expert center - patient association»: the point of view of a patient organization
- 11.20 Round table and discussion with international experts and patient associations
- 12.00 Break - Lunch Box

#### Ichthyosis

- 13.00 Ichthyosis diagnosis procedure, *dermatologist*
- 13.20 Newborn and child, *dermatologist*
- 13.40 Adult, *dermatologist*
- 14.00 Everyday life tips: *nurse, ergotherapist, physiotherapist, chiropodist, social worker*
- 14.30 Ears and eyes, *ophthalmologist-, Ear-Nose-Throat specialist*

15.00 The partnership «expert center - patient association»: the point of a patient organization

15.20 Round table and discussion with international experts and patient associations

### **Genetic Counselling**

16.00 Genetic counselling: by whom? for whom? what for?, *genetic counsellor, geneticist*

### **Genodermatoses and therapeutic education**

17.15 MAGEC experiences, *Social worker, dermatologists, nurses*

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## **14 October**

A full day session focusing on the analysis of the partners' survey: know-how techniques and international collaborations.

8.30 Registration

9.00 Introduction

A morning focused on know-how techniques to develop health care strategies adapted to each country's reality: the experience of patients, specialists and paramedics.

9.30 Epidermolysis Bullosa - *Coordinators*

10.00 Ichthyosis - *Coordinators*

10.30 Palmoplantar Keratoderma and Meleda -*Coordinators*

11.00 Coffee break

11.30 Neurofibromatosis - *Coordinators*

12.00 Xeroderma Pigmentosum - *Coordinators*

12.30 Ectodermal Dysplasia and Incontinentia Pigmenti - *Coordinators*

13.00 Lunch

An afternoon to discuss collaborative projects focusing on patient needs

14.30 Transversal approach / Summary of the answers to the questionnaire and proposals for collaborative projects - *Coordinators*

15.00 Eurordis, the Voice of Rare Diseases Patients in Europe

15.30 Coffee break

16.00 Collaborative projects focusing on patient needs

17.00 Conclusion

## 15 October

The objective of this session organized with Eurordis and Leem is to discuss with the industry:

- . solutions to improve access to medicines, cosmetics, medical devices and other products
- . grants for the training of specialists and nurses
- . any partnership focusing on patient needs

9.00 Medicines, cosmetics, medical devices and other products / State of the art

10.30 Coffee Break

11.00 Medicines, cosmetics, medical devices and other products / Partnership proposals

12.00 Conclusion - End of the meeting