Objectives

- Increase knowledge on cutis laxa, ectodermal and keratodermal disorders detection, diagnosis and management
- Develop and improve skills to manage common problems in different genodermatoses
- Encourage health care providers to adopt a multidisciplinary approach
- Update on last findings including the ectodermal dysplasia protein substitutive treatment, a model for other genodermatoses.
- Highlight key role of patient groups
- Network specialists

Target Participants

- This training is intended to senior health care providers as well as junior ones willing to get involved in the rare skin disease field.

Scientific Committee

- Prof. Christine Bodemer, Department of Dermatology, French Expertise Centre on Rare Skin Diseases, Hôpital Necker-Enfants Malades, APHP, IMAGINE Institute, Paris, France
- Prof. Johann Bauer, Department of Dermatology, Salzburger Landeskliniken gGesmbH, Paracelsus Medizinische Privatuniversität, Salzburg, Austria
- Dr. Smail Hadj-Rabia, Department of Dermatology, French Expertise Centre on Rare Skin Diseases, Hôpital Necker-Enfants Malades, APHP, IMAGINE Institute, Paris, France

Organizers

MAGEC *is a leading French and European Centre of Expertise in the field of rare skin diseases. MAGEC provides high level medical and paramedical multidisciplinary approach for children, adults and families with rare skin diseases.*

Genodermatoses Network *is the European and international network on rare skin diseases for patients and professionnals where partners work together to improve health care and social support for patients with severe and rare genetic skin diseases, and to promote a patient based approach.*

MAGEC-GNTS 2014

GENODERMATOSES NETWORK TRAINING SESSION

Imagine Institute, Paris
30-31 October 2014

WITH THE SUPPORT OF

FRT - Genodermatoses Network
European Academy of Dermatology and Venereology
Imagine Institute

UNDER THE PATRONAGE OF

Société Française de Dermatologie Pédiatrique

Contact: FRT - Genodermatoses Network
marie.guillou@fondation-r-touraine.org

PROGRAMME

Thursday Afternoon - October 30, 2014

14.00 - 16.00 INCONTINENTIA PIGMENTI / ECTODERMAL DYSPLASIA

14.00 Incontinentia Pigmenti: Diagnosis and Management
Christine Bodemer - Hôpital Necker Enfants Malades, Paris, France

14.30 Incontinentia Pigmenti: Neurological Involvement
Isabelle Desguerre - Hôpital Necker Enfants Malades, Paris, France

15.00 Anhydrotic Ectodermal Dysplasia: Diagnosis and Management
Smail Hadj-Rabia - Hôpital Necker Enfants Malades, Paris, France

15.30 Anhydrotic Ectodermal Dysplasia: New perspectives and Update
Kenneth Huttner - Edimer Pharmaceuticals

16.00 Coffee Break

16.30 - 17.30 CUTIS LAXA

16.30 Cutis Laxa: Diagnosis and Management
Bert Callewaert - Ghent University Hospital, Gent, Belgium

17.00 Cutis Laxa: Epigenetic Hypothesis
Pascal Sommer - Institut de Biologie et Chimie des Protéines, Lyon, France

PROGRAMME

Friday Morning - October 31, 2014

8.30 - 11.30 ICHTHYOSIS / PALMOPLANTAR KERATODERMA

8.30 What can we expect from a skin biopsy for the etiological diagnosis of hereditary ichthyosis in 2014?
Stéphanie Leclerc-Mercier - Hôpital Necker Enfants Malades, Paris, France

9.00 Non syndromic Ichthyosis: Practical Management
Angela Hernandez - Hospital Infantil del Niño Jesús, Madrid, Spain

9.30 An example of syndromic Ichthyosis: Dorfman Chanarin Syndrome
Frédéric Caux - Hôpital Avicenne, Bobigny, France

10.00 Coffee Break

10.30 Palmoplantar Keratoderma: Classification/Perspective
Antonio Torello - Hospital Infantil del Niño Jesús, Madrid, Spain

11.00 Long term use of retinoids
Maya El-Hachem - Ospedale Pediatrico Bambino Gesù, Rome, Italy

11.30 - 13.00 FOCUS ON SPECIFIC COMMON PROBLEMS IN DIFFERENT GENODERMATOSES

11.30 Skin Pain: what can we do?
Speaker to be confirmed

12.00 Pruritus: what can we do ?
Sonja Ständer - University Hospital Münster, Germany

12.30 Vitamin D and Genodermatoses
Khaled Ezzedine - Groupe Hospitalier Pellegrin, Bordeaux, France

13.00 - 13.15 CONCLUSION