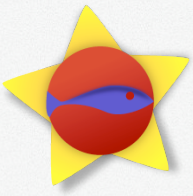

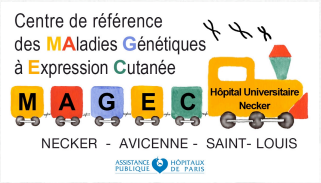

MAGEC-GNTS 2014

GENODERMATOSES NETWORK TRAINING SESSION

Highlight on cutis laxa,
ectodermal and keratodermal disorders

Focus on common problems in genodermatoses

Imagine Institute, Paris
30-31 October 2014

WELCOME MESSAGE

Dear Friends and Colleagues,

Welcome to Paris, welcome to the Imagine Institute, and welcome to MAGEC-GNTS, the 2014 Genodermatoses Network Training Session!

Since 2003, the Genodermatoses Network encourages initiatives to improve health care and social support for genodermatoses patients by promoting a patient-based approach. Training healthcare providers is a key issue to improve the management of patients.

Thanks to the support of the EADV, MAGEC-GNTS 2014 is a unique occasion to enhance our expertise on detection, diagnosis and management of cutis laxa, ectodermal and keratodermal disorders and further develop our skills to address common problems in genodermatoses such as the management of skin pain, pruritus and vitamin D.

Moreover, MAGEC-GNTS 2014 will be also a unique occasion to meet, discuss and share our expertise for the best health care. This will contribute to pave the way to a future European Reference Network for Rare Skin Diseases.

Thank you to all for your presence and for your participation!

Prof. Christine Bodemer

PROGRAMME

Thursday Afternoon - October 30, 2014

13.00 **Registration**

13.30 - 15.30 **INCONTINENTIA PIGMENTI / ECTODERMAL DYSPLASIA**

13.30 Incontinentia pigmenti: diagnosis and management
Christine Bodemer - Hôpital Necker Enfants Malades, Paris, France

14.00 Incontinentia pigmenti: neurological involvement
Isabelle Desguerre - Hôpital Necker Enfants Malades, Paris, France

14.30 Anhidrotic ectodermal dysplasia: diagnosis, management, new perspectives and update
Smail Hadj-Rabia - Hôpital Necker Enfants Malades, Paris, France
Christine Bodemer - Hôpital Necker Enfants Malades, Paris, France
Kenneth Huttner - Edimer Pharmaceuticals

15.00 Discussion

15.30 **Coffee break**

16.00 - 17.00 **CUTIS LAXA**

16.00 Cutis laxa: diagnosis and management
Bert Callewaert - Ghent University Hospital, Gent, Belgium

16.30 Cutis Laxa: epigenetic hypothesis
Pascal Sommer - Institut de Biologie et Chimie des Protéines, Lyon, France

17.00 - 17.30 **FOCUS ON SPECIFIC COMMON PROBLEMS IN DIFFERENT GENODERMATOSES (1)**

MAGEC-GNTS was granted 6 European CME credits.
Simultaneous translation into French will be available.

PROGRAMME

Friday Morning - October 31, 2014

9.00 - 11.00 ICHTHYOSIS / PALMOPLANTAR KERATODERMA

9.00 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

9.30 Non syndromic ichthyosis: practical management
Angela Hernandez - Hospital Infantil del Niño Jesús, Madrid, Spain

10.00 An example of syndromic ichthyosis: Dorfman Chanarin syndrome
Frédéric Caux - Hôpital Avicenne, Bobigny, France

10.30 Palmoplantar keratoderma: classification/perspective
Antonio Torrelo - Hospital Infantil del Niño Jesús, Madrid, Spain

11.00 Coffee break

11.30 - 13.00 FOCUS ON SPECIFIC COMMON PROBLEMS IN DIFFERENT GENODERMATOSES (2)

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

13.15 Snack

MAGEC-GNTS was granted 6 European CME credits.
Simultaneous translation into French will be available.

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 healthcare providers to adopt a multidisciplinary approach
- Update on latest findings including the ectodermal dysplasia protein substitutive treatment, a model for other genodermatoses.
- Highlight the key role of patient groups
- Foster networking amongst specialists

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
- Prof. Smail Hadj-Rabia, Department of Dermatology, French Expertise Centre on Rare Skin Diseases, Hôpital Necker-Enfants Malades, APHP, IMAGINE Institute, Paris, France

Venue

***Imagine*, Institute of genetic diseases**
24, boulevard du Montparnasse
75015 Paris

ORGANIZERS

GENODERMATOSES NETWORK

An international network on rare genetic skin diseases for professionals and patients

Centre de référence des MAladies Génétiques à Expression Cutanée

M A G E C

Hôpital Universitaire Necker

NECKER - AVICENNE - SAINT- LOUIS

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

WITH THE SUPPORT OF

European Academy of Dermatology and Venereology

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

Necker ENFANTS MALADES HÔPITAL UNIVERSITAIRE

imagine INSTITUT DES MALADIES GÉNÉTIQUES

astellas Leading Light for Life

LA ROCHE-POSAY LABORATOIRE DERMATOLOGIQUE

UNDER THE PATRONAGE OF

SFDP Société Française de Dermatologie Pédiatrique