FONDATION RENÉ TOURAINE

A pilot network to improve health care and social support for patients with severe and rare genetic skin diseases

Participants to the 2011 meeting

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SUPPORTING THERAPEUTIC PROGRESS IN DERMATOLOGY
- Better assessing the patient needs
- Fostering health care networks to improve dermatological care
- Developing continuing medical education
- Fostering clinical and therapeutic research

WHO ARE WE?
- An international non-governmental, non-profit organization founded in 1991
- In memory of René Touraine, who was at the origin of clinical and therapeutic dermatological research in France
- Gathering the instigators of the therapeutic progress in dermatology: dermatologists, researchers, patient associations, pharmaceutical and cosmetic industries and Health authorities

BOARD OF DIRECTORS
The Fondation René Touraine is supervised by a Board of Directors: This Board decides on overall strategy and budget.

President: L. Dubertret (France)
General Secretary: A. Touraine (France)
Treasurer: P. Choul (France)

Rightful Members:
- Representative of the French Ministry of Home Affairs
- Representative of the French Ministry of Health
- Representative of the French Ministry of Higher Education and Research
- Representative of the General Director of the Assistance Publique Hopitaux de Paris (Parisian hospitals)

Members chosen for their competence in the fields related to the Foundation’s activities:
- Representative of the ESDR: M. Gilliet (Switzerland)
- Representative of the EADV: E. Tschachler (Austria)

Representatives of the Founders:
- Prof. L. Dubertret
- A relative of Prof. R. Touraine
- One representative of a founding pharmaceutical industry
- One representative of a founding cosmetic industry

FOUNDERS’ ASSEMBLY
The Fondation René Touraine is advised by the Founders’ Assembly, gathering the industries who contributed to the Fondation René Touraine’s endowment. The Assembly is responsible for enlarging Fondation René Touraine’s influence sphere.

ABBOTT, BOOTS HEALTHCARE, CHAND. FONDATION LEO, SALDEMA INTERNATIONAL, JANSEN-CILAG, LABORATOIRES BAILLEUL, LABORATOIRES BERGADERM, LABORATOIRES PIERRE FABRE, LABORATOIRES ROCHE, LABORATOIRES SÉROBIOLOGIQUES, LA ROCHE POSAY LABORATOIRE, PHARMACEUTIQUE, L’ORÉAL, L.V.M.H., PFIZER, SCHERING-PLOUGH.

SCIENTIFIC BOARD
The Scientific Board decides to which candidates the Fondation René Touraine’s fellowships are awarded, as well as the organisation of the other scientific activities of the Fondation René Touraine.

President: I. Leigh (UK)
President-elect: T. Luger (Germany)
General Secretary: G. Tappeiner (Austria)

Psoriasis International Network Committee:
President: C. Paul (France)
President-elect: G. Tappeiner (Austria)
Members: M. Bagot (France), C. Griffiths (UK), L. Kemeny (Hungary), T. Luger (Germany), L. Puig (Spain)

Genodermatoses Committee:
President: J. Bauer (Austria)
President-elect: C. Bodemer (France)
Members: L. Bruckner-Tudermann (Germany), A. Hovnanian (France), M. Jonkman (The Netherlands), S. Karpati (Hungary), I. Leigh (UK), J. Mellerio (UK), H. Traupe (Germany), G. Zambruno (Italy)

e-Dermatology Portal Committee:
President: S. Aractingi (France)
President-elect: P. Filip (Portugal)
Members: L. Borradori (Switzerland), N. Dupin (France), M. de Rie (The Netherlands), G. Tappeiner (Austria)

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PARTNER COUNTRIES

Algeria, Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Egypt, France, Germany, Greece, Hungary, Iran, Italy, Kuwait, Lebanon, Libya, Morocco, The Netherlands, Palestinian Territories, Portugal, Romania, Saudi Arabia, Slovenia, Spain, Sudan, Syria, Tunisia, Turkey, United Kingdom, Yemen.

GENODERMATOSES NETWORK: ORIGIN & OBJECTIVES

The "Genodermatoses Network" (the Fondation René Tournaie network on rare genetic skin diseases, has been initiated in 2003 thanks to the involvement of dermatologists from the EU, Mediterranean and Middle-Eastern countries and the support of a founding member, Laboratoires Pierre Fabre.

Together Against Genodermatoses - a European project on rare skin diseases encouraging North-South collaborations.

In 2007, the "Genodermatoses Network" obtains a European recognition, with the 3-year project "TAG - Together Against Genodermatoses" co-financed by the European Commission (Agreement number 2007-3.3.401-140). The project was designed to develop a national and study network to better serve patients and families with rare genodermatoses.

WHAT ARE THE GENODERMATOSES?

- Rare genetic skin diseases very painful and painful for the daily life of the patients
- Many resulting in severe social handicap
- Many leading to social exclusion
- Very rare in EU Member States
- Higher prevalence in the Southern Mediterranean countries

GOAL

- IMPROVE THE QUALITY OF HEALTH CARE FOR PATIENTS SUFFERING FROM RARE GENETIC SKIN DISEASES

TOOLS

- GENODERMATOSES OUTPATIENT CLINICS IN EACH COUNTRY
- WORKING IN SYNERGY THROUGH NATIONAL NETWORKS
- SHARING EXPERIENCE AND KNOWLEDGE AT THE INTERNATIONAL LEVEL THROUGH CENTERS OF EXPERTISE

ACTIVITIES

- Networking experts on rare skin diseases
  - An annual international meeting to share experiences and develop new projects
  - Since 2003, 8 international working sessions gathered the partners of the "Genodermatoses Network"
  - Seven working groups to discuss the diagnosis and therapeutic strategies for each disease in a very practical way, medical, social and personal care
  - 6 disease-specific subgroups:
    - one for epidermolysis bullosa
    - one for ichthyosis
genodermatoses
    - one for palmoplantar keratoderma
    - one for neurofibromatosis
    - one for xeroderma pigmentosum
    - and one for other genodermatoses
- 1 cross-cutting subgroup: to develop a laboratory network to help patients and families with antenatal diagnosis
- Dermatologists, geneticists, scientists, patient representatives all participate in these groups

- Sharing information: a necessity for the progress of the health care of genodermatoses patients
  - A new website
  - To provide information about the "Genodermatoses Network", its partners, the working groups, the annual meetings, the main events of the network.
  - A newsletter providing information on the current situation of the "Genodermatoses Network".

- Evaluating the needs of patients
  - The opportunity to collect data on the genodermatoses at an international level
  - In 2011, a survey was carried out to learn more about the needs of patients and caregivers in each country participating to the «Genodermatoses Network»
  - Survey results are useful for scientists, dermatologists, Health authorities and Pharmaceutical industries
  - Survey completed by 111 co-participants from 16 countries.

HOW TO SUPPORT THE GENODERMATOSES NETWORK

- UPGRADE YOUR INVOLVEMENT IN DERMATOLOGY
- GET EXPERIENCE IN RARE DISEASES MANAGEMENT
- MEET THE DERMATOLOGICAL COMMUNITY OF THE EU, THE MIDDLE EAST AND THE MEDITERRANEAN AREAS WITHIN AN ETHICAL FRAMEWORK

Financial advantages:
Right to a tax deduction of 60% of the donation amount within a limit of 5% of the company’s turnover with the possibility of carrying forward over 5 years in case of deficit.
**THE GENODERMATOSES COMMITTEE OF THE FONDATION RENÉ TOURNAINE**

President: J. Bauer (Austria)
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As the TAG project’s coordinator, the President of the Fondation René Touraine has been designated as expert to the European Union Committee of Experts on Rare Diseases (EUCERD).

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