GENODERMATOSES NETWORK

www.genodermatoses-network.org

2003 until today.....

Prof. Christine Bodemer
President of the Genodermatoses Network Scientific Committee
Head of the Department of Dermatology,
Necker Enfants Malades Hospital, Paris
Coordinator of the French national Reference Centre for
Genodermatosis, MAGEC
and the national network for rare diseases of the skin (FIMARAD)
University Rene Descartes, Paris V, Institute Imagine
**Definition:** the European and international network on rare genetic skin diseases for professionals and patients

**Date of creation:** 2003

**Geographical Coverage:** 30 European, Mediterranean and Middle-Eastern countries

**Number of partner teams:** 52

**Goal:** to improve health care and social support for genodermatoses patients by promoting a patient-based approach

**Source of funding:** Fondation René Touraine, European Union, European Academy of Dermatology and Venereology, Corporate Donations, Private Donations
Goal: Patients

A patient-based approach
INITIAL OBJECTIVES

• To develop a patient-based approach

• To take into account the daily needs of patients and health care providers / Promote a multidisciplinary approach

• To improve health care and social support: by exchanging best practice and by increasing awareness of public health authorities

• To encourage the development of genodermatoses centers and patient groups in each country
The Genodermatoses Network develops an inclusive approach to involve in the network experts and centers taking care of patients.

The Genodermatoses Network works in close collaboration with other networks such as Geneskin and EB-Clinet as well as patient groups and alliances, i.e Debra International, Eurordis and Orphanet...‡
More than 400 monogenetic genodermatoses have been defined based on molecular research. FOCUS ON 5 GROUPS OF RARE SKIN DISEASES

- Epidermolysis Bullosa in collaboration with EB-Clinet
- Ichthyosis
- Palmoplantar Keratoderma
- Ectodermal Dysplasia and Incontinentia Pigmenti
- DNA repair disorders - Xeroderma Pigmentosum
From 2003 until today.....

1-The different steps of the development
2- The realizations
3-The perspectives
1-GENODERMATOSES NETWORK
IN 4 DATES

From 2003 until today.....
2003-2008: Genodermatoses in Mediterranean

- Development of a Mediterranean and Middle-Eastern Clinical Network - The first clinical network on rare skin diseases

- Organization of six international meetings getting together dermatologists, pediatricians, paramedics, patients, scientists, industry, public health officials

- Involvement of Ministries of Health / Strategies to integrate genodermatoses into major public health issues (chronic/rare diseases, handicap, cancer)

- Dedicated working groups on epidermolysis bullosa, ichthyosis, palmoplantar keratoderma, xeroderma pigmentosum, ectodermal dysplasia and incontinentia pigmenti
2008-2011: Together Against Genodermatoses  
EU Grant : TAG 2007 335

- A European Reference Network (ERN) Pilot Project  
  According to the Cross-Border Healthcare Directive, European Reference Network (ERN) will provide the framework for healthcare pathways for Rare Diseases patients through a high level of integrated expertise.

- Co-funded by the European Union - TAG n° 2007 335 under the Health Programme
2008-2011: Together Against Genodermatoses
EU Grant : TAG 2007 335

✓ 48 Partners from European and Non European Countries including 14 patient groups

✓ European Reference Network Pilot Project

✓ More than 30 training sessions

✓ 3 international meetings

✓ State of the art of the management of Rare Skin Diseases in Europe
2011 –2014:
Towards a European and International Network for Rare Skin Diseases

✓ A dedicated Genodermatoses Network Scientific Committee with European leaders in the rare skin diseases field
  a president and a president-elect
  J Bauer (Austria) and C Bodemer (France)

✓ A Partnership with the main European Society of Dermatology

✓ Meeting of the EADV Genodermatoses Task Force with Debra International at the European Academy of Dermatology and Venereology Congress, October 5, 2013 in Istanbul, Turkey
The 2014-2017 leaders of the Genodermatoses Network Scientific Committee are:

- Christine Bodemer, President (France)
- Maya El-Hachem, President-elect (Italy)
- Johann Bauer, Past President (Austria)
2-GENODERMATOSES NETWORK

SERVICES

1-Identifying health care providers and patient groups

2-Evaluating patient needs

3-Training health care providers
1-Identifying health care providers and patient groups

An interactive directory for patients and professionals making possible to identify in each country

- Genodermatoses consultations
- Research teams
- Patient organisations
Medical and Paramedical consultations for patients with rare skin diseases

Dear Madame, Dear Sir,

The Genodermatoses Network is the European and International Network on Rare Skin Diseases for Professionals and Patients.

An interactive map directory is available on www.genodermatoses-network.org

This survey should help us to have a clear view of medical/paramedical consultations for patients and families available in your country or abroad.

Please note that this information will be kept confidential within the network.

We would appreciate very much if you could take 10 minutes to answer that survey.

Should you need further information, please send us an email: office@genodermatoses-network.org

Thank you very much for your help.

Best regards.

Christine Bodemer, President of the Genodermatoses Network
Maya El-Hachem, President-elect of the Genodermatoses Network
Johann Bauer, Past-president of the Genodermatoses Network

2014 Survey

- An international survey on medical and paramedical consultations for patients with rare skin diseases
- Prepared with Eurordis
- 14 Debra groups have answered!
- THANK YOU VERY MUCH!
Networking experts at the national, European and international levels
2- Evaluating patient needs

1 extensive survey to evaluate the needs of patients and of healthcare professionals

- 67 completed surveys in 16 countries
- Hint and tips
- Drugs and medical devices - 15 categories
- Network
  - Consultations for patients with genodermatoses,
  - Diagnostic techniques
  - Genetic counseling
  - Taking care of patients with severe genodermatoses
  - Guidelines for care and support
  - Training of professionals
  - Patient groups
  - Therapeutic patient education
  - Epidemiological monitoring and records
  - Telemedicine
  - Research projects

Paris, Magec-Necker meeting, TAG 2011
Multicentre consensus recommendations for skin care in inherited epidermolysis bullosa

May El Hachem,1 Giovanna Zambruno,2 Eva Bourdon-Lanoy,3 Annalisa Ciasulli,1 Christiane Buisson,3 Smail Hadj-Rabia3,4 Andrea Diociaiuti,1 Carolina F Gouveia,5 Angela Hernández-Martín,6 Raul de Lucas Laguna,7 Mateja Dolenc-Voljč,8 Gianluca Tadini,9 Guglielmo Salvatori,10 Cristiana De Ranieri,11 Stephanie Leclerc-Mercier,3 and Christine Bodemer3,4

1Dermatology Unit, Bambino Gesù Children’s Hospital, IRCCS, Piazza S. Onofrio, 4, 00165 Rome, Italy
2Laboratory of Molecular and Cell Biology, Istituto Dermopatico dell’Immacolata, IDI-IRCCS, Rome, Italy
3Department of Dermatology, Necker–Enfants Malades Hospital, National reference centre for Genodermatoses (MAGEC), 149 rue de Sèvres, 75015 Paris, France
4Université Paris Descartes - Sorbonne Paris Cité, Institut Imagine, Paris, France
5Dermatology University Clinic, Hospital de Santa Maria, Centro Hospitalar Lisboa Norte EPE, Lisbon, Portugal
6Department of Dermatology, Hospital Infantil del Niño Jesús, Madrid, Spain
7Department of Dermatology, Hospital Infantil La Paz, Madrid, Spain
8Department of Dermatovenerology, University Medical Centre Ljubljana, Ljubljana, Slovenia
9Section of Dermatology, Fondazione IRCCS Cà Granda-Ospedale Maggiore Policlinico di Milano, Milan, Italy
10Neonatal Intensive Care Unit, Department of Medical and Surgical Neonatology, Bambino Gesù Children’s Hospital, IRCCS, Rome, Italy
11Clinical Psychology Unit, Bambino Gesù Children’s Hospital, IRCCS, Rome, Italy
3-Training health care providers

31 training sessions including

• 15 practical training sessions for specialists and nurses in the dermatology departments of centres of expertise

• The 2011 training session was organized in Paris (Magec-Necker) and focussed on EB
Multidisciplinary Training on EB, 13 October 2011
Hôpital Necker - Enfants Malades

Chair: Christine Bodemer

- Classification, diagnosis procedure, J. Bauer (dermatologist)
- Health care: the role of the medical doctor, E. Bourdon-Lanoy (dermatologist)
- Nursing, I. Corset (nurse)
- Everyday life tips: V. Bughin (physiotherapy), S. Chaumon (nurse), E. Deladrière (ergotherapy), C. Gennari (physiotherapy)
- Hand surgery, S. Guero (plastic-surgeon)
- Oral care, B. Kverneland (dentist)
- Nutrition difficulties, C. Lambe (gastroenterologist - nutritionist)

- The partnership «expertise center - patient group»: the point of view of EBAE, the French Epidermolysis Bullosa patient organization, G. Verdot
- Round table and discussion with international experts and patient group:
  J. Dart (Debra International), H. El-Sadat (mother of a young patient, Egypt), G. Verdot (EBAE, France) and the patient associations from other countries
30-31 October, 2014
Paris, France

Training session on
• Incontinentia Pigmenti / Ectodermal Dysplasia
• Cutis laxa
• Ichthyosis / Palmoplantar Keratoderma

• FOCUS ON SPECIFIC COMMON PROBLEMS IN DIFFERENT GENODERMATOSES: PAIN / PRURITUS / VITAMIN D
3-Perspectives:

TOWARDS A EUROPEAN REFERENCE NETWORK FOR RARE SKIN DISEASES
According to the Cross-Border Healthcare Directive, European Reference Network (ERN) “will provide the framework for healthcare pathways for Rare Diseases patients through a high level of integrated expertise”.

What is a European Reference Network (ERN)?
European Reference Network (ERN)?

- will facilitate access to diagnosis, treatment and provision of affordable, high-quality and cost-effective healthcare

- will serve as focal points for medical training and research, information dissemination and healthcare evaluation.
The Delegated Decision (Art. 17) and Implementation Decision (Art. 16) did include that ERNs should be patient centred.
IMPROVE THE QUALITY AND SAFEY AND ACCESS TO HIGHLY SPECIALISED HEALTHCARE

- Patient Empowerment
- Teaching and Training
- Research
- National and international collaboration with other centers of expertise and networks
- Outcome measures and quality control
- Communication e-Health Tools
- High Level Patient Management Good Quality and Safe Care

GENODERMATOSES NETWORK
European Reference Network (ERN) Organisation

• will bring together highly specialised healthcare providers from different EU Member States in areas where expertise is rare

• Not to create new providers, but rather to link existing highly specialised providers.
European Reference Network (ERN) Organisation

- will be organised for clusters of diseases - not a single disease
- are expected to be operational by 2016

All together
i.e. Debra International, EB-Clinet, the Genodermatoses Network
we have to be prepared for the call for networks
(4 quarter 2015)
Learn more about the Genodermatoses Network
Register your patient group
Subscribe to our newsletter

www.genodermatoses-network.org