



**6th Genodermatoses in Mediterranean working session
1st TAG meeting**

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Strategies for the health care
and social support for patients
and families with EB in
Romania

Epidemiologic data

- 36 patients officially recognized with EB (2008)
 - Source: http://www.ms.ro/fisiere/proiecte_normative
- In fact there are around 50 patients with EB
- In our department in Cluj-Napoca there are followed up:
 - 9 patients with EB
 - 22 patients with ichthyosis
 - 9 patients with neurofibromatosis
 - 2 patients with xeroderma pigmentosum

Assessment of needs of patients and costs of the diseases

- Typical needs: lesion dressings, surgical procedures, medical treatment, nutritional supplements, social and psychological support.
- The average cost for the needs of a patient with EB is officially estimated at 1000 RON (238€)/month (2008)
 - Source:
http://www.ms.ro/fisiere/proiecte_normative/132_304_Modificari%20Ordin%20574%20.doc

Development of a national network for EB in Romania

- Implementation of a database for storing the following informations: clinical, genealogy tree, paraclinic investigations, other information is missing at the national level
- In 2006 University of Medicine and Pharmacy Cluj-Napoca, Romania, Dept Dermatology
 - www.degeb.org

The management of EB

- Multidisciplinary team consisting of dermatologist, pediatrician, surgeon, geneticist
 - Brasov and Cluj-Napoca

The management of EB

- Specialized treatment:
 - Medical treatment:
 - Few skin care products and ointments paid by the assurance system
 - silicone coated foam dressings (Mepilex, Mepitel) - few in our department
 - Periodical evaluation
 - General evaluation
 - Performing standard laboratory explorations
 - Evaluation of the skin and associated lesions
 - Evaluation of the nutritional status (anemia; malnutrition; proteins, vitamins and minerals deficiency)

Establishing a center for molecular diagnostic of EB

- Department of Dermatology, University of Medicine Cluj-Napoca – in 2006
- Collecting of genetic material (blood and skin biopsy samples) from the patient and its family
- Performing antigen mapping for EB type differentiation
- Performing the DNA molecular analysis for identification of the genetic mutation

Associations of patients with EB

- Organization for EB patients and their families – Mini Debra
 - Increasing the awareness about EB
 - A connection between patients, doctors, international institutions, sponsors.
- www.minidebra.ro
- Debra Association, professional, Brasov

The development of collaborations on the European level

- Training exchange programs
- Cooperation in the fields of diagnosis and treatment
 - Cooperation with the expert centers for diagnosis: Dept Dermatology in Freiburg, Prof. Dr. Leena Bruckner-Tuderman
 - State-financed treatment abroad for severe illness that cannot be treated in Romania (OG 28/2003)
 - <http://sas.mmssf.ro/compendiumLegislativ.php?id=142>