Romania

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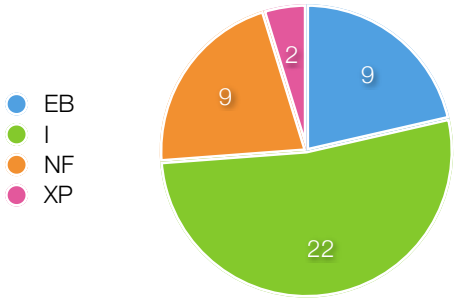
Epidemiological data are available at a national level for epidermolysis bullosa and in the department of dermatology of the Faculty of Medecine and Pharmacy of Cluj-Napoca for other genodermatoses

The data available on a national level are those concerning the epidermolysis bullosa. According to the data available on the website of the Ministry of Health in Romania in 2008, 36 patients are officially recognized as epidermolysis bullosa patients. But in reality, they are aroung 50 epidermolysis bullosa patients. In Cluj-Napoca's department, 9 epidermolysis bullosa patients, 22 ichthyosis patients, 9 neurofibromatosis patients and 2 xeroderma pigmentosum patients are followed.



Maladie / Syndrome	Number of cases
Ichthyosis (I)	22
Epidermolysis Bullosa (EB)	9
Neurofibromatosis (NF)	9
Xeroderma Pigmentosum (XP)	2
Total	**42**

Number of cases of Epidermolysis Bullosa (EB), Icthyosis (I), Palmoplantar Keratoderma (PPK), Neurofibromatosis (NF), Xeroderma Pigmentosum (X) in the Department of Dermatology, University of Medicine and Pharmacy, Cluj-Napoca, Romania

The epidermolysis bullosa health care in the dermatology departments of Brasov and Cluj-Napoca

The multidisciplinary team is composed of a dermatologist, a pediatrician, a surgeon, a geneticist. Some skin care products are reimbursed by health insurance. Some specific dressings for the health care of epidermolysis bullosa (Mepilex, Mepitel) are available in the dermatology department of Cluj-Napoca. The regular follow up of patients includes a general checkup, lab examinations, skin and lesions examinationination, a nutritional checkup (anemia ; malnutrition ; lack of proteins, vitamins and minerals).

The needs for epidermolysis bullosa are: dressings, surgery, medical treatments, nutritional supplement, social and psychological support. According to the informations available on the website of the Ministry of Health in Romania, the average cost of these needs is assessed to 1000 RON = 238€ per month (2008).

The Degeb project: the development of a centre for molecular diagnosis of epidermolysis bullosa

The Dermatology Department of the Faculty of Medecine of Cluj-Napoca has initiated the Degeb project in 2006, www.degeb.org. This project aimed at developing molecular diagnosis of epidermolysis bullosa in Romania with the development of new technics for research, diagnosis, treatment and prevention of epidermolysis bullosa and developing a national register on genodermatoses.

This project consisted in taking sample of patients and families. This project enabled the achievement of the antigene mapping for the identification of different types of epidermolysis bullosa and the molecular analysis for mutations identification.

Mini Debra, the organisation for epidermolysis bullosa patients in Romania

Mini Debra, www.minidebra.ro, gathers epidermolysis bullosa patients and their families. It aims at promoting the knowledge of epidermolysis bullosa. It is also a link between patients, doctors, international organisations and sponsors. There is also a Debra organisation in Brasov which gathers health professionals.

International collaborations for training, diagnosis and treatments

‣ 2008 & 2009

These collaborations are in the framework of training exchange programmes. They are also developing in the diagnosis field with the centre of reference for diagnosis of Prof. Leena Bruckner-Tuderman from the dermatology department of Freiburg in Germany.

The Romanian government can finance treatements abroad for the severe diseases that cannot be treated in Romania (OG 28/2003): http://sas.mmssf.ro/compendiumLegislativ.php?id=142).