

Slovenia

Mateja Dolenc-Voljč , Vlasta Dragoš , Vesna Tlaker-Žunter, Marko Potočnik, Faculty of Medicine of Ljubljana, Department of Dermatology and Veneorology, Zaloška 2, Ljubljana, Slovénia

Four dermatology departments providing a multidisciplinary approach

Slovenia has a population of 2 millions of inhabitants with 4 dermato-venerology departments including 2 university hospitals. All the departments have developed a multidisciplinary approach.

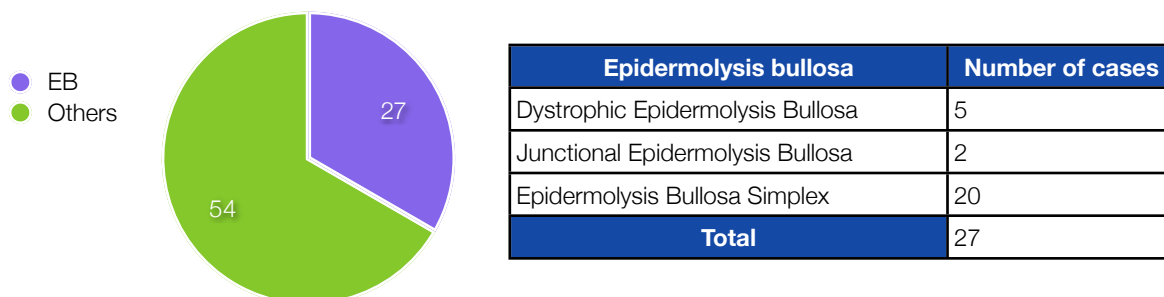
Available data for epidermolysis bullosa and Darier disease

54 cases of Darier disease have been spotted and 27 cases of epidermolysis bullosa. Among the 27 cases of epidermolysis bullosa:

- dystrophic epidermolysis bullosa: 5 patients including 3 children
- junctional epidermolysis bullosa: 2 patients
- simplex epidermolysis bullosa: 20 children in 4 families,
- the exact number of adult patients is unknown and for some of them the disease is slightly expressed.

Some cases of congenital ichthyosis, congenital erythroderma ichthyosiforms and neurofibromatosis were recently spotted.

For the other genodermatoses (palmoplantar keratoderma, vulgaris ichthyosis, anhidrotic ectodermal dysplasia, incontinentia pigmenti) the number of cases is unknown.



Number of cases of Epidermolysis Bullosa (EB) and Darier disease (Others).

The dermato-venerology department of Ljubljana: a specialised centre for the health care of genodermatoses children and the health care of epidermolysis bullosa adults and children

• All the children affected by genodermatoses are followed in the dermato-venerology department of Ljubljana

- The health care of genodermatoses children (except epidermolysis bullosa children)

All the children affected by genodermatoses are followed in the dermato-venerology department of Ljubljana in cooperation with pediatricians and other specialists. Parents are trained to answer the needs of children and provide adapted care. Cooperation with social workers is well developed.

- The health care of epidermolysis bullosa children

Children are regularly followed (at least 3 times a year). They are hospitalized at least once a year for a thorough examination. Skin lesion dressings are regularly renewed at home by trained nurses. Since 1993, diagnosis is confirmed for all children on the histologic level and through electron microscopy.

• All the epidermolysis bullosa patients are followed in the dermato-venerology department of Ljubljana

- A multidisciplinary team

In 2009, a multidisciplinary team has been formed for the health care of epidermolysis bullosa. This team works thanks to the collaboration between dermatologists, pediatricians, geneticists, ophthalmologists, stomatologists, plastic surgeons, internists, psychologists. This team aims also at increasing the knowledge of epidermolysis bullosa among the specialists and improving the possibilities of treatment for patients.

- The health care of epidermolysis bullosa children

See above.

- The health care of epidermolysis bullosa adults

All the dystrophic and junctional epidermolysis bullosa patients are hospitalized once a year for thorough examination.

Other dermatology departments manage adults affected by genodermatoses other than epidermolysis bullosa

Adults patients with genodermatoses other than epidermolysis bullosa are followed in departments other than Ljubljana's. Regular check ups are done by dermatologists. Their health care is multidisciplinary, following the existing recommendations, but adapted to the local context. Home care is provided by nurses.

The costs of the disease are covered by insurance companies with an exception for dressings, creams and topic treatments

Debra Slovenia : an organisation for epidermolysis bullosa patients in Slovenia

Debra Slovenia was created in 2005. This organisation gathers epidermolysis bullosa patients and their relatives. It facilitates meeting of patients and sharing experience. Debra Slovenia also brings support for social integration of patients. It has a role of education, training and information to patients and their families and health professionals: education and information on news in the field of skin care and treatments for patients. Debra Slovenia also provides specific dressings for epidermolysis bullosa care. Debra Slovenia raises general public awareness. It also raises funds to answer the needs of patients.

European collaborations to favour exchange between patients, improve diagnosis and training of health professionals

• Cooperation between Debra Slovenia and Debra Croatia

Debra Slovenia and Debra Croatia have organised joint meetings.

• Contacts with the Department of Dermatology and Molecular Dermatology of Fribourg in Germany

These contacts aim at providing genetic analysis for dystrophic and junctional epidermolysis bullosa patients.

• Training health professionals in United-Kingdom and Croatia

Two dermatologists, two nurses and a pediatrician participated in a symposium on epidermolysis bullosa in United-Kingdom and in Croatia in 2009.

The projects of the dermato-venerology department of Ljubljana to improve the health care of genodermatoses patients in Slovenia

- Prepare a national register on genodermatoses in Slovenia
- Organise a national network between the dermatology departments for genodermatoses
- Reinforce collaborations in Europe
- Improve diagnosis and treatment
- Train young dermatologists and other health professionals