

Croatia

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Services for epidermolysis bullosa patients are well developed thanks to a great mobilisation of Debra Croatia helped by the medical personnel

• Debra Croatia fights for a better health care of epidermolysis bullosa patients

In 2008-2009, Debra Croatia fought for the health care of patients above the age of 18. Debra Croatia develops numerous activities for patients and families: improvement of the daily life of patients through actions of education, social insertion, general public awareness raising through medias, organisation of exhibition and gala, a book for children. Their website: www.debra-croatia.com.

• Debra Croatia works in synergy with rare diseases patients' organisation

Debra Croatia is a member of Eurordis, of the Croatian Association of rare diseases patients, of the Croatian federation of health organisations, of the *Génodermatoses et Méditerranée* and TAG networks. Debra Croatia is member of Debra International and has very close links with Debra Bosnia and Herzegovina as well as Debra Serbia.

• The 1st Regional Symposium (Mediterranean- Central Europe- East Europe) on Inherited Epidermolysis Bullosa took place in Zagreb

The 1st Regional Symposium on Inherited Epidermolysis Bullosa (Mediterranean- Central Europe- East Europe) took place in Zagreb on April 3-4, 2009. It was organised by the Association of Dermatology and Venerology of the Croatian Medical Organisation, by Debra Croatia and the centre of reference on Epidermolysis Bullosa of the Ministry of Health and Social Protection.

The centre of reference for the epidermolysis bullosa within the Department of Dermatology and Venerology, of the University Hospital of Zagreb

This centre has been created in May 2008.

The multidisciplinary committee for the health care of epidermolysis bullosa of the Ministry of Health and Social Protection

This committee is co-ordinated by Dr. Slobodna Murat-Sušić, dermatologist-venerologist and pediatrician involved in the management of epidermolysis bullosa.

Towards a national plan for rare diseases

Debra Croatia is member of the Association for Rare Diseases of the Croatian Medical Organisation. In 2010, the 1st conference on rare diseases was held in Croatia in the framework of the Europlan project which aims at promoting the development of national plans for rare diseases.