

Tunisia

The Tunisian Genodermatoses group was represented by Monia Kharfi, Dept. of Dermatology, Charles Nicolle Hospital, Tunis, Tunisia

Seven university hospital dermatology departments in Tunisia

There are 7 university hospital dermatology departments in Tunisia: four in Tunis, one in Sousse, one in Monastir, one in Sfax.

Genodermatoses are recognized as a handicap, a public health priority in Tunisia

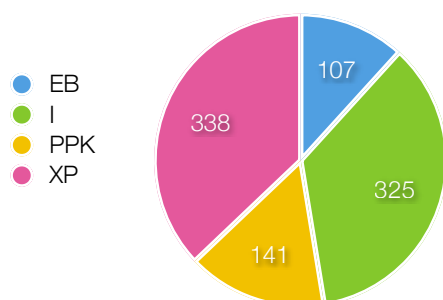
In 2006, the law widens the definition of handicap. Genodermatoses are recognized as disabling diseases. Genodermatoses patients have the same rights as disabled people: a «handicap card», free care in public health structures, free drugs available in hospitals (such as the Neotigason), free access to transportation (urban and 50% off inter-urban).

Data available in 4 university hospital dermatology departments and a mapping for xeroderma pigmentosum

There is no national prevalence established for the different genodermatoses in Tunisia. Presented data are from studies and reports of the 4 Tunisian university hospital dermatology departments: Charles Nicolle Hospital, Military Hospital, Sousse Hospital and Sfax Hospital.

A xeroderma pigmentosum mapping was made by the Habib Thameur Hospital (Tunis) team. It spotted 338 cases. The number of affected children is estimated to more than 800 cases. The highest concentration of patients is in the North-West where its frequency is sometimes above 1/100.

Disease	Habib Thameur	Charles Nicolle	Militaire	Sousse	Sfax	Total
Epidermolysis Bullosa	/	38	14	15	40	107
Ichthyosis	/	148	17	60	100	325
Palmoplantar Keratoderma	/	49	2	40	50	141
Xeroderma Pigmentosum	338	/	/	/	/	338
Total	338	235	33	115	190	911



Number of cases of Epidermolysis Bullosa (EB), Ichthyosis (I), Palmoplantar Keratoderma (PPK) and Xeroderma Pigmentosum (XP)

The assessment of the costs of the health care for epidermolysis bullosa (1.100 euros per patient and per year), ichthyosis (2.200 euros per patient and per year), palmoplantar keratoderma (1.150 euros per patient and per year)

• Epidermolysis bullosa

For daily care, sterile compresses, sofra-tule, gauzes, cleansing products, antiseptics, emollients, local antibiotics and antibiotic and vitamin treatments are used. The costs of the health care of an epidermolysis patient are assessed to 2000 Tunisian dirhams for a year (1.100 euros). The cost of biological checkups and potential explorations must be added to these expenses.

• Ichthyosis

Acitretine (Neotigason*), emollients, antimycotics and antihistamines are used for the health care of ichthyosis patients. The costs of the health care of an ichthyosis patient are assessed to 4.000 Tunisian dirhams for a year (2.200 euros). During the antenatal period, the cost of care in specialised centre within the different departments of neonatology of Tunis, Sousse and Sfax and biological checkups and potential explorations must be added to these expenses,

• Palmoplantar Keratoderma

Acitretine (Neotigason*), emollients, antimycotics and antihistamines are used for the health care of a palmoplantar keratoderma patient. They are assessed to 2.100 Tunisian dirhams for a year (1.150 euro). The cost of biological checkups and potential explorations must be added to these expenses.

A centre of expertise for the health care of xeroderma pigmentosum patients at the Habib Thameur Hospital (Tunis) and pediatric dermatology specialised consultations in 4 university hospitals

Xeroderma pigmentosum patients are managed, for most of them, in the centre of expertise of the Habib Thameur Hospital. Charles Nicolle Hospital (90% genodermatoses), the Children Hospital of Tunis, the Military Hospital have pediatric dermatology specialised consultations. La Rabta Hospital also opened a dermatology consultation in the spring of 2009.

Three medical genetics departments

There are 3 genetics departments: one in Tunis, one in Sousse, one in Sfax.

Three molecular biology laboratories

There are 3 molecular biology laboratories in Tunis: one at the Pasteur Institute, one at the Faculty of Medecine and one in the private sector.

Improve the health care of epidermolysis bullosa, ichthyosis and palmoplantar keratoderma: education of families and access to care devices and sun screen

Within the different medical teams, the interest in the health care of genodermatoses patients has increased. Specific actions have been developed in each department, among other the patient recruitment.

• The education of families

The doctors develop actions favouring education of families through explanations of the disease, education to the health care of children and help to home care.

- Epidermolysis bullosa: education and training of families

In each dermatology department, doctors and care personnel develop actions favouring education of patients and their families. Epidermolysis bullosa health care training is organised within the dermatology department of Charles Nicolle Hospital. Families are trained to provide adapted care to epidermolysis bullosa newborns. A trained nurse gives this training in day hospital, in a dedicated room. Parents are accompanied the first weeks to evaluate the quality of the care provided. A psychological management is also available for patients and families.

- Ichthyosis : education and training of families

During the antenatal period, health care is provided in the different neonatology departments of the university hospitals of Tunis, Sousse, Monastir and Sfax in collaboration with the dermatologist. Families are trained to provide adapted care to ichthyosis newborns. A trained nurse gives this training in day hospital, in a dedicated room. Parents are accompanied the first weeks to evaluate the quality of the care provided. After that, home care is organised and managed with regular checkups in day hospital consultation.

- Palmoplantar keratoderma

The health care of palmoplantar keratoderma patients is symptomatic treatment made at home. Patients are regularly seen in consultations. The treatment of frequent fungic secondary infections is made through antifungal.

Reinforced collaborations between dermatology, genetics and molecular biology departments

Collaboration has been reinforced between the dermatology departments of Tunis, the genetics department of Charles Nicolle Hospital and molecular biology department of the Pasteur Institute of Tunis.

The development of severe genodermatoses patients' organisations

- Creation of the organisation for Help to xeroderma pigmentosum children in 2008

Recently, and with the help of the French xeroderma pigmentosum organisation, an organisation for xeroderma pigmentosum patients has been developed. Website: [www.xeroderma pigmentosum-tunisie.org.tn](http://www.xeroderma-pigmentosum-tunisie.org.tn)

- Development of an organisation for epidermolysis bullosa patients in Sfax

- Development of a genodermatoses organisation in Tunis

Collaborations with French teams

Several teams have contacts and collaborations with foreign teams, mainly French.

The objective of the Tunisian genodermatoses group: pool and structure the initiatives on the national level to optimize efforts

Génodermatoses et Méditerranée enabled the reinforcement of individual initiatives in the field of training, research and care. These initiatives participate in improving the health care of genodermatoses. This action also helped raising decisionmakers, health professionals and families awareness.