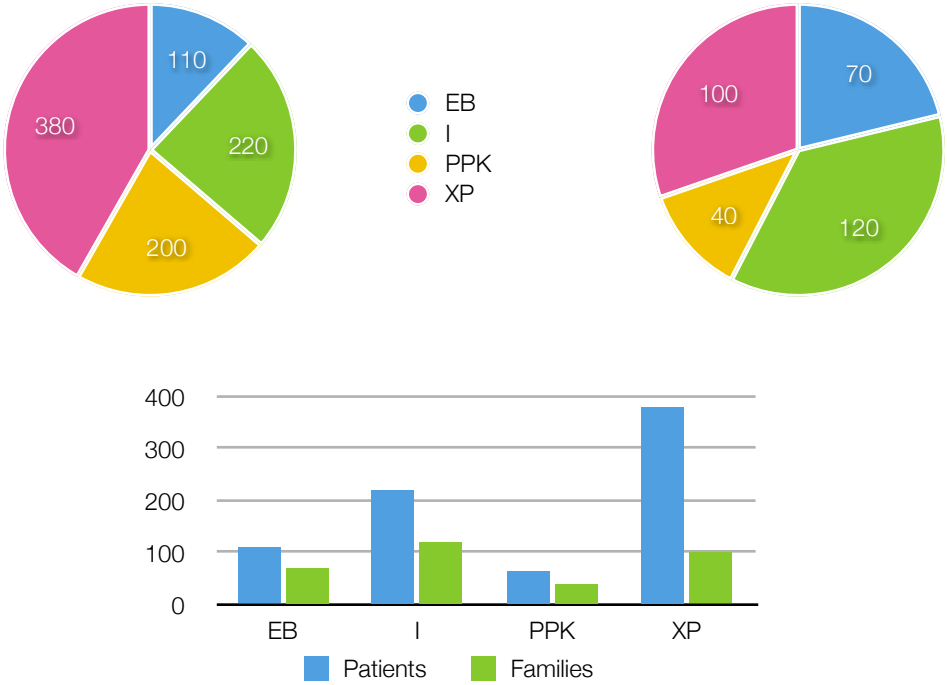
Algeria

Bakar Bouadjar, Department of Dermatology, University Hospital of Bab El Oued, Algiers

Collected data in the 2 university hospital departments of dermatology of Algiers

Available data come from the University Hospitals' dermatology departments of Algiers, Bab El Oued and Mustapha. Generally, the recruitment of patients increased with the reactivation of the sentinel network introduced in Algeria. Other genodermatoses for which data have not been communicated are present in Algeria: Kindler syndrom, Papillon-Lefèvre syndrom, Chanarin Dorfman Syndrom.



Number of patients and families with Epidermolysis Bullosa (EB), Recessive Ichthyosis(I), Mal de Meleda (PPK), Neurofibromatosis (NF), Xeroderma Pigmentosum (XP)

Disease	Number of patients	Number of families
Inherited Epidermolysis Bullosa	110	70
Épidermodysplasies verruciformes	26	22
Recessive Ichtyosis	220	120
Mal de Meleda	65	40
Scléroses Tubéreuses de Bourneville	28	10
Xeroderma Pigmentosum	380	100
Total	829	362

A sentinel network to point out the severe genodermatoses cases in link with dermatologists and pediatricians.

A medical sentinel network has been introduced in Algeria to point out the severe genodermatoses cases and address them to dermatology departments of the University Hospitals of Algiers. In the meantime, pediatrician are now involved in the management of youg severe genodermatoses patients.

A network for the management of xeroderma pigmentosum in Algiers

Sentinel doctors within the country are in touch with the departments of dermatology of the University Hospitals of Bab El oued and Mustapha for the health care of patients. This management is made in collaboration with the plastic and reconstructive surgery departments of Prof. Joucdar and Prof. Mitiche.

A budget of more than 200 000 euros for the purchase of drugs for genodermatoses promised in 2008

A budget of 19 565 000 DA = 207 867 euros has been granted by the Head of Finances of the Ministry of Health to the 2 Unversity Hospitals' dermatology departments of Algiers, Bab El Oued and Mustapha to buy drugs. This budget has been assessed as follow:

- Inherited Epidermolysis bullosa: 125 000 dinars (1 329 euros) for 50 patients = 225 euros per patient and per year,
- Ichthyosis: 12 320 000 dinars (130 893 euros) for 220 patients = around 600 euros per patient and per year,
- Palmoplantar Keratoderma: 1 400 000 dinars (14 474 euros) for 150 patients = around 100 euros per patient and per year,
- Xeroderma Pigmentosum : 5 720 000 dinars (60 772 euros) for 200 patients = around 300 euros per patient and per year.

This budget is said to be renewable each year with the possibility of increasing its amount if necessary. But, to date, the budget has not been allocated yet.

A budget of 125 000 euros for antenatal diagnosis of xeroderma pigmentosum

A budget has been granted for equipping and the reagents of laboratories whose activity is focused on diagnosis and genetic studies of rare diseases. This budget has essentially be used for antenatal diagnosis of xeroderma pigmentosum. The assessment of the budget has been made in collaboration with Dr. Zghal from the University Hospital of Habib Thameur in Tunisia.

Organisations to help patients and families

• Organisations to help patients

Organisations support hospitalized children and chronic diseases patients:

- Le Souk, an organisation of medical students

Le Souk accompanies chronical diseases patients. This organisation has already organised activities for xeroderma pigmentosum and ichthyosis patients. Their website: www.lesouk.org

- Amine, an organisation for hospitalized children

Amine is located in the University Hospital of Bab El Oued. It aims at helping hospitalized children.

• Organisations and volunteer groups bring support to dermatological and metabolic diseases patients

Organisations of patients are developing in Algeria with the involvment of doctors. But there is no severe genodermatoses patients' organisation yet.

- Organisation of metabolic diseases patients' parents
- Psoriasis organisation
- Xeroderma Pigmentosum Algeria: a volunteer group at Oran (West of Algeria) brings its help and support to xeroderma pigmentosum patients. www.xeroderma pigmentosumalgerie.org