

Greece

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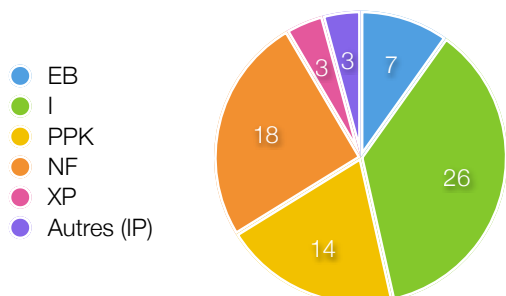
The development of an online epidemiological database

The advantages of this online database are numerous. It is an internet application: a browser is the only tool to install in each centre. For the connection, the user has an internet address and a password. Data are kept in the same place and can be easily managed to avoid registering the same patient twice. This database is evolutive. Hospitals can access the database at the same time, which speeds up the data capture. Saving is automatic. Data are available as soon as they are registered, which enables reports on the base of the most recently registered data.

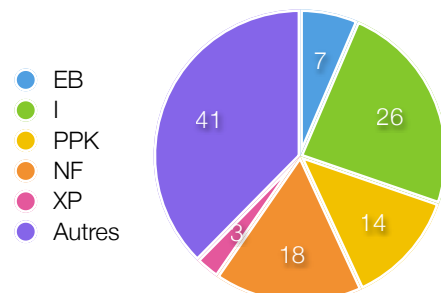
2008-2009 data from Athens and Larisa Hospitals

Disease	Number of cases
Ichthyosis	26
Epidermolysis Bullosa	7
Neurofibromatosis	18
Palmoplantar Keratoderma	14
Xeroderma Pigmentosum	3
Others*	41
Total	109

* Other Genodermatoses	Number of cases
Darier + Hailey-Hailey	17
Porokeratosis	13
Tuberous Sclerosis	4
Incontinentia Pigmenti	3
Ehlers-Danlos	1
Genotrichosis	3



Number of cases of epidermolysis bullosa (EB), ichthyosis (I), palmoplantar keratoderma (PPK), neurofibromatosis (NF), xeroderma pigmentosum (XP) and incontinentia pigmenti (IP).



Number of cases of epidermolysis bullosa (EB), ichthyosis (I), palmoplantar keratoderma (PPK), neurofibromatosis (NF), xeroderma pigmentosum (XP) and other genodermatoses.

Patients' needs

Patients' needs are: the health care by public health services, access to drugs, medical devices and cosmetics, development of centres of expertise for a better treatment, access to better care and genetic counseling, a better knowledge of the disease, of the evolution of the disease especially for children and information on new treatments. The biggest health insurance of Greece covers 10 boxes of emollient cream by month for ichthyosis patients.

Two centers of expertise

A centre of expertise for ichthyosis and palmoplantar keratoderma has been created in Athens, as well as a centre for neurofibromatosis in Larisa.