

Libya

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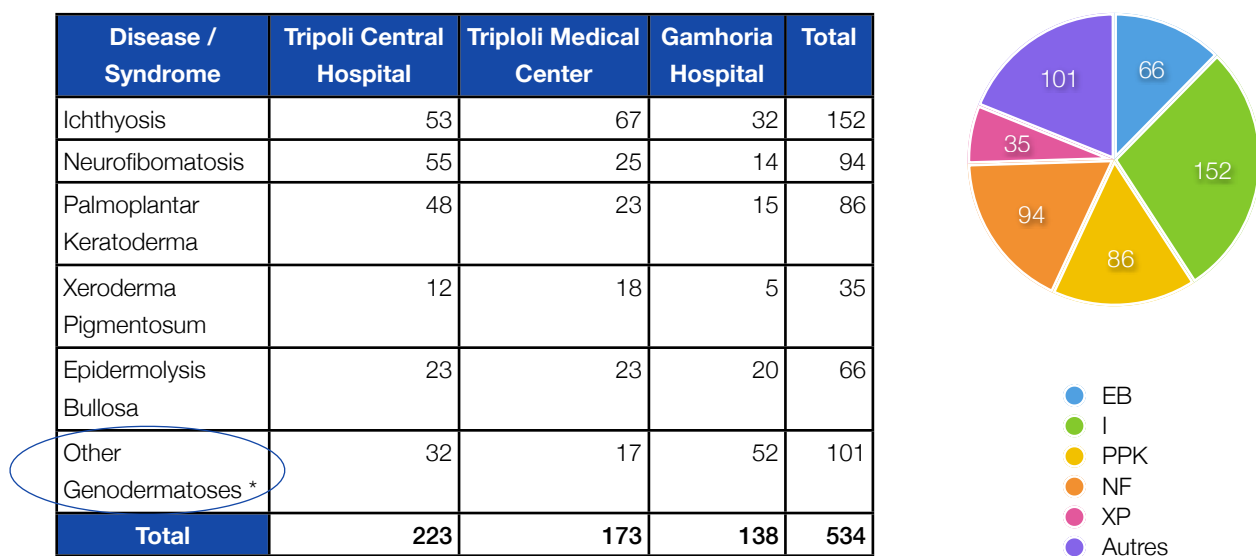
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Presented by Dr. Mohamed El Hashme / LGP TASK FORCE: GENO SITE.pub 4.mht

Almost 300 new cases in 2009

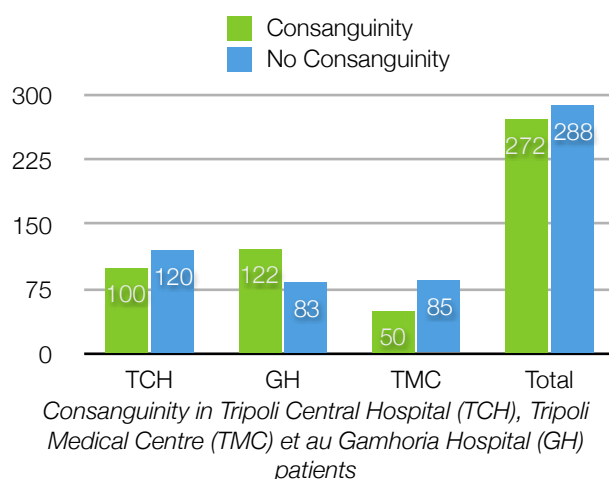
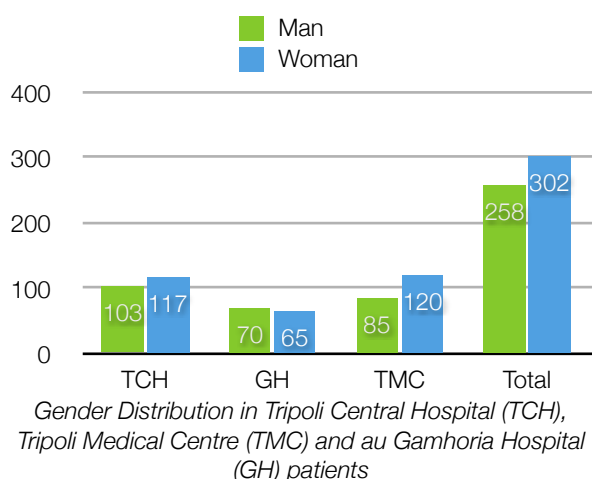
The collect of epidemiological data is done in a particular context. Libya's total area is 1,759,540 Km² with a population of 6,039,000 inhabitants and a limited number of dermatologists. Data are collected in 3 regions: North West, South West and East. Data are not available in the South of the country. 560 cases have been registered: 220 at the Tripoli Central Hospital, 205 at the Tripoli Medical Centre and 135 at the Gamhoria Hospital.



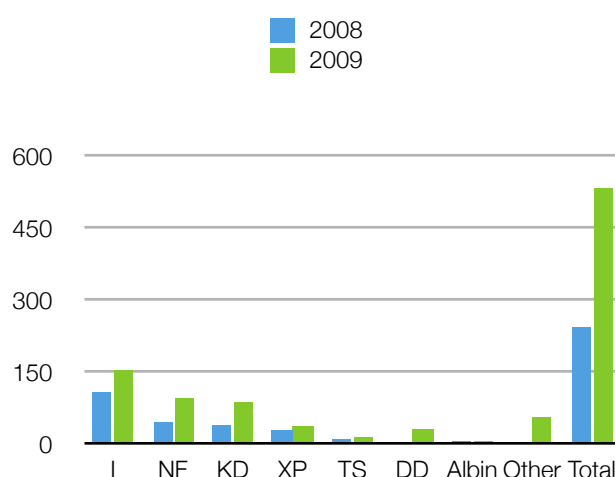
2009 Register: Number of cases of epidermolyses bullosa (EB), recessive ichthyosis (I), palmoplantar keratoderma (PPK), neurofibromatosis (NF), xeroderma pigmentosum (XP) and other genodermatoses in Tripoli Central Hospital (TCH), Tripoli Medical Centre (TMC) et Gamhoria Hospital (GH)

* Other genodermatoses	Tripoli Central Hospital	Triploli Medical Center	Gamhoria Hospital	Total
Tuberous Sclerosis	10	2	3	15
Albinism	3	0	1	4
DD	4	5	20	29
Others	15	10	28	53

2009 Register: Number of cases other genodermatoses in Tripoli Central Hospital (TCH), Tripoli Medical Centre (TMC) et Gamhoria Hospital (GH)



Disease / Syndrome	2008	2009
Ichthyosis	105	152
Neurofibromatosis	43	94
Palmoplantar Keratoderma	37	86
Xeroderma Pigmentosum	27	35
Epidermolysis Bullosa	17	66
Tuberous Sclerosis	9	12
DD	0	29
Albinism	4	4
Others	0	53
Total	242	531



Cases in 2009 and 2008 in Tripoli Central Hospital, Tripoli Medical Centre et Gamhoria Hospital

Working groups focused on the epidemiological data collect and on the management of each disease

These groups gather regularly under the coordination of:

- Data Center Coordinator: Dr. Amal Merset, Tripoli Central Hospital
- East and South Data Center Coordinator: Dr. Mariam Bozgia, Gamhoria Hospital, Benghazi
- West Data Center Coordinator for Xeroderma Pigmentosum: Dr. Aisha Najat A. Mormesh, Tripoli Central Hospital
- Epidermolysis Bullosa Group Coordinator and Website: Dr. Abdelaziz H. Mohamed, Al-Bayda Hospital
- Ichthyosis Group Coordinator: Dr. Bashir Zendah, Tripoli Medical Centre
- Palmoplantar Keratoderma Group Coordinator : Dr. Reyan Elmaghrabi, Tripoli Medical Centre
- Neurofibromatosis Group Coordinator and Spokesperson: R. Omran Omar Bugrein Gamhoria H., Benghazi
- Xeroderma Pigmentosum Group Coordinator: Dr. Ali Saleim Lashab, Al-khoms Hospital
- Darier Disease Group Coordinator : Dr. Kafia Elhafi, Tripoli Central Hospital
- Tuberous Sclerosis Group Coordinator: Dr. Mohamed Elhashme, Tripoli Central Hospital, Paediatric Society
- International Coordinator: Prof. Gamal Duweb, Gamhoria Hospital, Benghazi

The development of a multidisciplinary approach

Specialists involved in the management of patients are pediatricians, pediatric surgeons, ophthalmologists, orthodontists, maxillofacial surgeons, pharmacists, urologists, neurologists, plastic surgeons.

Training and raising the awareness of care personnel, patients, families and general public

- 2008 & 2009

Training given to care personnel is made through lectures in Faculties of Medicine. Actions to educate patients are done with families. General public awareness raising is done through the media.

A regular supply of drugs and dressings

Drugs are free and with priority access. To ensure the regular supplying of drugs and dressings, the head of surveillance of drugs joined the Libyan genodermatoses group.

Charities

There is no severe genodermatoses patients' organisation. A social support is brought through the following organisations: Safe childhood, International African Arab Organization for Disabled Rights (IAAODR). Collaborations are viewed with Waatasimo, Shabab Libya Organization, Amal Orphan Association.

Access to diagnosis and genetic counseling difficulties

Antenatal diagnosis, diagnosis of specific cases and genetic counseling are difficult to develop because of the cultural context.