



**6th Genodermatoses in Mediterranean working session
1st TAG meeting**

May 22 - May 25, 2009, Greece

Tunisian Genodermatoses Group
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Initiatives for a better health
care of severe
genodermatoses in Tunisia

Law widening the notion of handicap (2006)

- Genodermatoses recognised as disabling diseases and enabling the grant of the « handicap card »
 - Care within health public structures are free of charge
 - Drugs usually available in hospitals (such as the Néotigason*) are free of charge
 - Means of transportation are free of charge (urban and 50%off inter-urban)

- Epidemiological data
- Assessment of the health care cost
- Referral centers for health care of patients and their families
- Strategy for genodermatoses' health care
- National network
- Collaboration on the European level

Epidemiological data

- No national prevalence established for the different genodermatoses in Tunisia
- Cartography for XP
- Studies and reports of University Hospital dermatology departments
- 7 University Hospital dermatology departments in Tunisia
 - Tunis (4)
 - Sousse
 - Monastir
 - Sfax
- We have the data from 4 departments:

H. Charles Nicolle, Hopital Militaire, H. of Sousse and H. of Sfax

Epidemiological data

- Data from 4 departments on 7
 - Tunis
 - H. Charles Nicolle
 - H. Militaire
 - Sousse
 - Sfax

Epidemiological data

- Epidermolysis Bullosa (EB): 107 patients
- Data from 4 departments (on 7)
 - Tunis:
 - H. Charles Nicolle: 38 patients
 - H. Militaire: 14 patients
 - Sousse: 15 patients
 - Sfax: 40 patients

Epidemiological data

- Ichthyosis 325 patients
- Data from 4 departments (on 7)
 - Tunis:
 - H. Charles Nicolle: 148 patients
 - H. Militaire: 17 patients
 - Sousse: 60 patients
 - Sfax: 100 patients

Epidemiological data

- KPP: 141 patients
- Data from 4 departments (on 7)
- Tunis:
 - H. Charles Nicolle: 49
 - H. Militaire: 2
- Sousse: 40
- Sfax: 50
 - 2 main families of Meleda
 - 1 family of Buschke-Fischer

Assessment of health care cost

- Evaluation of genodermatoses' health care needs per patients and per year
 - Epidermolysis bullosa
 - Ichthyosis
 - KPP

Assessment of health care cost

EB:

- Daily care: sterile compresses, sofratulle, gauzes, cleansing products, antiseptics, emollients, local antibiotics
- Antibiotic treatments
- Vitamin supplement

2000 dt/year/patient → 1100 euros

Assessment of health care cost

Ichthyosis:

- Acitrétine (Neotigason*)
- Emollients
- Antimycotics and antihistamines

4000 dt/year/patient → 2200 euros

Assessment of health care cost

KPP:

- Acitrétine (Neotigason*)
- Emollients
- Antimycotics and antihistamines

2100 dt/year/patient → 1150 euros

Referral centers for health care of patients and their families

- Center of XP expertise mainly at Habib Thameur Hôpital
- Specialised consultations of pediatric dermatology
 - Hôpital Charles Nicolle (90% genodermatoses)
 - Hôpital d'Enfants de Tunis
 - Hôpital Militaire
 - Hôpital la Rabta: new since a few weeks
- Several departments of medical genetics: Tunis, Sousse and Sfax
- Molecular biology laboratories
 - Tunis: Institut Pasteur, Medical faculty and a private one
 - Sousse
 - Sfax

Strategy for genodermatoses health care

- Individual actions according to the departments and the recruitment
- Stimulation of the interest on genodermatoses in the different medical teams
- No codified national strategy

Strategy for genodermatoses health care

- Education of the patients and their families by the doctors and the medical staff of each dermatology department
- Health care training in the hospital

Genodermatoses health care training for the medical staff

- EB: Hôpital Charles Nicolle
 - Education of the families for the care of new-born EB and ichthyosis
 - Day hospital with a care room
 - Trained nurse
 - Checking the first weeks to evaluate the quality of the health care
 - Psychological support and care for the family

- Ichthyosis:
 - Neonatal period:
 - Health care in the different neonatology departments of the CHU of Tunis, Sousse, Monastir and Sfax in collaboration with the dermatologist
 - Education of the families

 - After:
 - Reimbursement of health care at home
 - Regular medical checking in outpatients department

Education of patients

- KPP:
 - Symptomatic treatment at home
 - Reduction of skin thickness
 - Regular consultations
 - Treatment of frequent fungic secondary infections
⇒ antifungals

Improvement of the health care's quality

- Explanations and doctor-patient communication
- Education of families (support for the parents of EB babies to help handle the situation)
- Advice
- Help for health care at home by providing sterile compresses and dressings for EB (Sfax , HCN , HM)
- Providing of sun screen thanks to laboratories' help

National network

- Reinforced collaboration between dermatology departments for the health care of genodermatoses
- Development of a closer collaboration between dermatology, genetics and molecular biology departments
 - Institut Pasteur, genetics departments of Hopital Charles Nicolle and different dermatology departments of Tunis

Development stage

Collaboration on a European level

- Several teams are in touch and have personal collaborations with foreign teams, French essentially

Development of patients' organisations

- « Les enfants de la lune »: XP
- EB organisation: in Sfax, in process
- Genodermatoses organisation: in Tunis, in process

Conclusion

- Since the project « Génodermatoses et Méditerrané »
 - Reinforcement of the individual initiatives (training, research, care) improving genodermatoses health care
 - A better awareness-raising of decision-makers, health actors and families
 - Initiatives need to be put together and structured on a national level to optimize the efforts