



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

May 22 - May 25, 2009, Greece

Egyptian Genodermatosis Group

Coordinator: Emad El-Gamal,
Damietta Faculty of Medicine,
Al-Azhar University, Egypt

Egyptian project

Involved Depts of Dermatology of the Faculties of Medecine:

- Alexandria
- Damiette
- Assiout*
- Minieh*
- Sohag*

* Assiout, Minieh et Sohag are located in the South of Egypt, a region with a high consanguinity / high number of patients

- These centers will be the reference centers for the region.

Scientific collaboration

Excellent and fruitful collaboration between:

- Kasr Al Aini Hospital, Cairo University, Faculty of
- Medicine (Prof. El Darouti)
- National Research Center, Cairo (Prof. Ghada El Kamah)

Registered cases

- Hospital Kasr Al Aini, Cairo University:
 - EB 130,
 - XP 97,
 - Ichthyosis 55.
- National Research Center, Cairo:
 - EB 7,
 - Ichthyosis 7,
 - XP 3,
 - Ectodermal dysplasia 12,
 - NF 6,
 - Others:14.

Registered cases

- Al Haud Al Marsoud Hospital, Cairo:
 - Ichthyosis 33,
 - EB 22,
 - XP 12,
 - PPK 12,
 - Other: 171.
- Dept. of dermatology, Damiette:
 - EB 2,
 - XP 5,
 - Ichthyosis 2,
 - Other 3.

Registered cases

- Dept. of dermatology, Alexandria:
 - EB 2,
 - XP 8,
 - Ichthyosis 59,
 - NF 15,
 - Other 7.
- Research Medical Institute, Alexandria :
 - EB 3,
 - Ichthyosis 8,
 - Ectodermal dysplasia 8,
 - NF 2,
 - Other 2.

Total Registered cases

- EB 166.
- Ichthyosis 164.
- XP 125.
- Ectodermal dysplasia 20.
- NF 23.
- PPK 12.
- Le reste: 197.

EBD Health care

- Prof. El-Darouti, Kasr Al Aini Hospital, Cairo is involved in clinical trials in RDEB patients (89) using cell based therapies. He has performed intravenous administration of specialized cells, called non-hematopoietic bone marrow stem cells (BMNHSC), from allogeneic matching donors. The medical treatment is modified (therapeutic rotation: retinoids and topical phenytoin)
- Prof. El Darouti was invited in US to discuss EBD treatment with 13 experts on February 20, 2009, "Genetics, Stem Cell Biology and Stem Cell Transplantation in Epidermolysis Bullosa"

XP Health Care

- Systemic retinoids daily.
- Systemic cyclo-oxygenase inhibitors daily.
- Topical 5 FU bid for 4 weeks repeated every 6 months.
- For SCC, BCC and SK: Shave excision and postoperative INF sublesional 3x/week for 8 weeks.

Ichthyosis Health Care

For lamellar ichthyosis and ichthyosiform erythroderma:

- Acitretin 0.3 mg/kg/day.
- Sodium bicarbonate baths for 20 minutes twice daily followed by urea 10% cream application.
- Tazarotene application(whole body in the evening to be washed next morning) 2x/week.
- Sugar paste application(as in hair removal) to most noticeable areas once every 2 weeks.

www.genodermatosis.eg.net

- Dr Amin Sharobim, Dept. Of Dermatology, National Research Center, Cairo has developed the website of the Egyptian Genodermatosis group.
- With the support of
 - ENSTINET (Egyptian National STI Network)
 - Prof. Ghada El Kamah
 - And other members of the Egyptian Genodermatosis group

Education / Training

- In Cairo, agreement with ENSTINET to organize training session for family doctors, pediatricians and dermatologists.
- In Alexandria, the Society of Dermatology with Caritas-Alex got the official agreement to organize similar training sessions.

EB patients

- Yasmin's second paintings exhibition:
 - March 21st – 29th , 2009
 - at El Sawi Wheel Center - zamalek
- Yasmin donated money to Al Kasr El Aini Hospital for the treatment of EB children

Towards a genodermatoses patients association

Mrs Hanaa Sadat, Mother of Yasmin, with the support of Prof. El Darouti, work hard to set up a genodermatoses patients association.