

Egypt

Presentation has been made by the Dr. El Gamal, Faculty of medicine of Damiette, University Al-Azhar, Egyp. He coordinates the Egyptian Genodermatoses Group.

The Egyptian Genodermatoses Group grows and develops its website

- 5 departments of dermatology join the Egyptian Genodermatoses Group

The *Egyptian Genodermatoses Group* is coordinated by the Dr. El-Gamal. 5 departments of dermatology join the Egyptian Genodermatoses Group: the dermatology departments of the Faculties of Medecine of Alexandria, Damiette, Assiout, Minieh and Sohag. Assiout, Minieh and Sohag are in the South of Egypt, a region with a high number of patients due to consanguinity, among other. These centres have been identified as the future centres of reference of the region.

Les centres identifiés en Egypte sont les suivants :

- National Research Center (NRC), Cairo: Dept. of Clinical and Molecular Genetics, Dept. of Dermatology
- Medical Research Institute, Alexandria: Dept. of Genetics
- Kasr Alainy Faculty of Medecine, Cairo University: Dept. of Dermatology
- El-Haud el Marsoud Hospital, Cairo: genodermatoses outpatients
- Shark Al Medina Hospital, Alexandria: Dept. of Dermatology
- Ain Shams Faculty of Medecine: Dept. of Dermatology
- Menia Faculty of Medecine: Dept. of Dermatology
- Sohag Faculty of Medecine: Dept. of Dermatology
- Assiut Faculty of Medecine: Dept. of Dermatology
- Damietta Faculty of Medecine: Dept. of Dermatology
- Alexandria Faculty of Medecine: Dept. of Dermatology

- The website of the Egyptian Genodermatoses Group : www.genodermatosis.eg.net

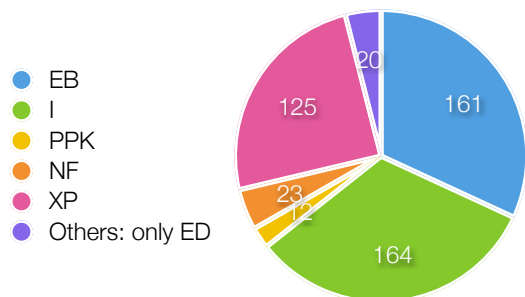
Dr. Amin Sharobim from the Dermatology Department of the National Research Centre in Cairo has developed the website of the *Egyptian Genodermatoses group* with the support of ENSTINET (Egyptian National STI Network), Prof. Ghada El Kamah and other members of the group.

Epidemiological data have been collected in 6 partner centres of the Egyptian Genodermatosis Group

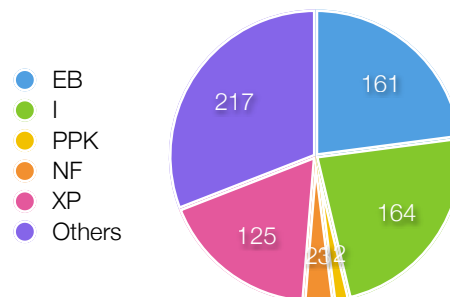
Data have been collected in the following centres:

- Kasr Alainy Faculty Hospital, Cairo University: Dept. of Dermatology
- National Research Center (NRC), Cairo
- El-Haud el Marsoud Hospital, Cairo: genodermatoses outpatients
- Damietta Faculty of Medecine: Dept. of Dermatology
- Alexandria Faculty of Medecine: Dept. of Dermatology
- Medical Research Institute, Alexandria: Dept. of Genetics

Unisvertisy Hopital / Health Center	EB	I	NF	PPK	XP	Others	Total
Kasr Alainy Faculty Hospital, Cairo University	130	55	0	0	97	0	282
National Research Center (NRC), Cairo	7	7	6	0	3	26 including 12 ectodermal dysplasia	49
El-Haud el Marsoud Hospital, Cairo	22	33	0	12	12	171	250
Damietta Faculty of Medecine	2	2	0	0	5	3	12
Alexandria Faculty of Medecine	2	59	15	0	8	7	91
Medical Research Institute, Alexandria	3	8	2	0	0	10 including 8 ectodermal dysplasia	23
Total	166	164	23	12	125	217 including 20 ectodermal dysplasia	707



Numbers of cases of Epidermolysis Bullosa (EB), Recessive Ichthyoses(I), Palmoplantar Keratoderma(PPK), Neurofibromatoses (NF), Xeroderma Pigmentosum (X) and Ectodermal Dysplasia (Others: only ED)



Numbers of cases of Epidermolysis Bullosa (EB), Recessive Ichthyoses(I), Palmoplantar Keratoderma(PPK), Neurofibromatoses (NF), Xeroderma Pigmentosum (X) and other genodermatoses (Others)

Health care strategy for Recessive Dystrophic Epidermolysis Bullosa, Lamellar Ichthyosis and Xeroderma Pigmentosum

Genodermatoses are managed according to the following protocols:

• Clinical trials using cell therapy for the health care of Recessive Dystrophic epidermolysis Bullosa

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 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".

• Xeroderma Pigmentosum 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 (lamellar ichthyosis and ichthyosiform erythroderma)

- Acitretin 0.3 mg/kg/day
- Sodium bicarbonate baths for 20 minutes twice a day 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

Training in Cairo and Alexandria for general practitioners, pediatricians and dermatologists

In Cairo, an agreement has been signed with ENSTINET, the Egyptian National STI Network to organise training sessions for general practitioners, pediatricians and dermatologists. In Alexandria, the Association of Dermatology of Alexandria and the charity association Caritas-Alex got the official agreement to organise similar training sessions.

A scientific collaboration in Egypt in the genodermatoses field

This collaboration is developing between 2 institutions: the University Hospital of Kasr Al Aini (Prof. El Darouti) and the National Research Centre (Prof. Ghada El Kamah).

Financial and social support for epidermolysis bullosa patients

Mrs Sadat, Yasmin's mother, an epidermolysis bullosa patient, has set up several actions to help people with epidermolysis bullosa in Egypt.

Mrs El Sadat presented these actions at the 2006, 2007 and 2008 working sessions.

She works with Prof. El-Darouti to develop a severe genodermatoses patients association.

ZOOM>>> The experience of Yasmin: fighting against Epidermolysis Bullosa in Egypt

Yasmin is 13 years old. She is the youngest artist in Egypt. Her second painting exhibition took place on March 21-29 2009.

Being a recessive dystrophic epidermolysis bullosa patient, she raises the awareness of general public through medias, her friends, her drawings, flyers. Yasmin has sold 350 calendars and gave the earnings to the epidermolysis bullosa kids from the Al Kasr El Aini hospital.

Learn more: www.yasminwitheb.net -You-tube: yasmin el samra yasminelsamra@hotmail.com - Face book