FONDATION RENE TOURAINE

Genodermatoses and Mediterranean

2007 Report

An action supported by

Pierre Fabre

FONDATION RENE TOURAINE

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The 2007 working session was organized in Alexandria, Egypt by

Alexandria Society of Dermatology, Venereology and Andrology

Under the auspices of

Mr. Amr Moussa, Secretary General of the League of the Arab States

Prof. Dr. Hatem El Gabaly, Minister of Health and Population, Egypt

Mr. Major General Adel Labib, Governor of Alexandria, Egypt

Dr. Mohamed-Cheikh Biadillah, Minister of Health, Morocco

Mr. A. Tou, Minister of Health, Population and Hospital Reform, Algeria

Dr. Mohamed Ridha Kechrid, Minister of Public Health, Tunisia

Dr. Abdul Kareem Rasee, Minister of Health and Population, Yemen

Dr Hamad Bin Abdullah Almanee, Minister of Health, Saudi Arabia

Mr. Philippe Bas, Minister of Health and Solidarity, France

Ass. Prof. Neven Ljubicic, Minister of Health and Social Welfare, Croatia

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LEs Entreprises du Médicament, France

Genodermatoses and Mediterranean
Towards a Euro Mediterranean network against genodermatoses

Genodermatoses and Mediterranean
Towards a Euro Mediterranean network
Against genodermatoses

BACKGROUND

Genodermatoses are the subject of a long-standing and efficient collaboration in genetics in the Mediterranean and the Middle-Eastern countries.
Many actions have been undertaken to improve medical care and social life of the patients. However, no comprehensive solution has been given to patients and their family because of the small number of these pathologies, the challenges faced in mobilizing the necessary skills and expertise, the isolation of patients, the lack of community services and the social exclusion linked to skin diseases.

Fondation René Touraine and Laboratoires Pierre Fabre launched the "Genodermatoses and Mediterranean" initiative in 2003 thanks to the support and the involvement of medical doctors and specially dermatologists, scientists, politicians, public health officials from the Euro Mediterranean and Middle-Eastern countries.

This initiative aims at:
- Improving the health care and the social support of the patients and families affected by severe skin diseases
- Promoting clinical research programmes dedicated to evaluate and fulfill the patients' needs
- Fostering the development of a Euro Mediterranean network of friendship and expertise
- Promoting dermatology as a key specialty on the medical and social levels

5 WORKING GROUPS TO ADDRESS THE NEEDS OF PATIENTS AND FAMILIES

Severe genodermatoses challenges

Genodermatoses are genetic skin diseases. They are various (around 300) almost all rare. They usually break out at birth or early in life.

In waiting for the gene therapy, symptomatic treatments are of major importance. The medical care involves many specialties. Furthermore the access to medicines and medical devices is often difficult. Patients and families have to face health care and social protection challenges such as late diagnosis, difficulty to mobilize the necessary skills and expertise, lack of awareness of the existence of centers specialized in the treatment of these diseases, obstacles to the identification of community medical and paramedical resources, insufficient coordination in between physicians and hospitals, insufficiently trained caregivers, limited access to information affecting authorities, MDs, patients and families, etc.

The burden of severe genodermatoses is huge for patients and families. Their social exclusion, disability, short life expectancy make this population very vulnerable. Social life is very hard: access to school, to work, and to leisure activities is almost impossible.

A public health issue in the Euro Mediterranean area

For these reasons, severe genodermatoses are a public health issue in the Euro-Mediterranean area and in the countries of the Middle East.

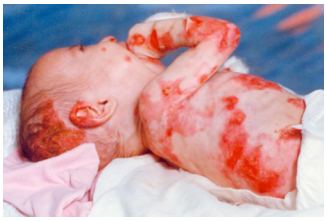
In Europe, genodermatoses fall within a new public health priority: the rare diseases one.
The prevalence of genodermatoses is higher in the South of the Mediterranean basin and in the countries of the Middle-East because of - depending on the countries- cultural factors, consanguine marriages, inter community marriages, isolated cultural and religious sects, economical concerns, limited access to public education resources and to public health resources, resistance to issues such as birth control, or pre-natal diagnosis.
According to each country policies, genodermatoses are included in different public health priorities such as genetic disorders, chronic diseases, handicap, cancer, rare diseases.

2007: organization of 5 working groups

The partners in "Genodermatoses and Mediterranean" have targeted genodermatoses with a severe repercussion on quality of life of patients and families, leading to a huge social handicap. In 2007, they have gathered in 5 international and multidisciplinary task forces: epidermolysis bullosa, severe ichthyosis, palmoplantar keratoderma, xeroderma pigmentosum other severe genodermatoses (specially 8 groups of diseases: Anhydrotic ectodermal dysplasia and incontinentia pigmenti, Neurofibromatosis, Cutis laxa, Genotrichoses, Tuberous sclerosis, Melanocytic disorders, Trichothiodystrophy, Ehlers Danlos syndrome).

Epidermolysis bullosa

Mohamed Abdelaziz Alahlafi[1]



Epidermolysis bullosa (EB) encompasses a group of heritable skin disorders manifesting with easy blistering and erosions as a result of minor trauma to the skin. The condition generally starts at birth or soon after.The EB conditions result from genetic defects of molecules in the skin concerned with adhesion. Loss of adhesion results in blister formation. Healing is impaired in some forms and scarring after blister formation may cause deformities, fusion of the fingers and toes, and contracture deformities. If the mouth and esophagus are involved, blistering and scarring lead to feeding and swallowing difficulties. Generalized blistering may be complicated by infection, sepsis. The outcome depends on the severity of the illness. There are three main types of epidermolysis bullosa:

- Epidermolysis bullosa simplex (EBS)
- Junctional epidermolysis bullosa (JEB)
- Dystrophic epidermolysis bullosa (DEB)

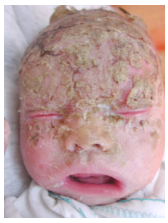
Death and disability are highly variable according to type. Particularly for the more severe forms of the disease, the effect on the quality of life is very marked and perhaps more than with any other skin disease. With the JEB, nearly 90% die from infection in the first year of life. Death from skin cancer is common between the ages of 15 and 35 but in the milder forms, life expectancy is unaffected.

[1] Faculty of Medicine, Omar Al-Mukhtar University, Al-Baida City, Libya

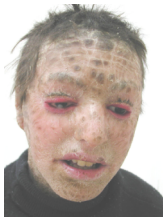
All of the different types of epidermolysis bullosa are generally inherited. Therefore, having a family history of the disease, especially an affected parent, is a risk factor. Prenatal diagnosis can be made using fetal skin biopsy or analysis of the fetal DNA.
The treatment of EB patients should be individualized to each patient and tailored to the severity of the disease. A multidisciplinary team approach is most beneficial to the EB patient. New treatment modalities, new wound care products, and research with tissue engineered skin and gene therapy may improve the overall treatment of patients with EB.

Severe ichthyosis

Bakar Bouadjar[2]
(translated from French)



Recessive ichthyosis is an inherited keratinisation disorder, which appears in most cases at birth with a collodion baby (the newborn is encased in a collodion membrane).
The later development leads to death if a fast management in a specialized facility is not begun because of thermo genesis and metabolism disorders. If the baby survives, his/her skin becomes covered with very disabling thick and dry scales (fish-like).



Treatment with retinoid is efficient but only symptomatic; it has many side effects and it is very expensive. Moreover, in some Mediterranean and Middle-Eastern countries as in Algeria, families often come from a modest background and these drugs are not paid by social security.

Christine Bodemer[3]
The ichthyoses have been defined clinically by the presence of visible scales, with in most cases a thickened stratum corneum histopathologically. So the clinical diagnosis of an ichthyosis is easy. The characteristics of the scales (fine or thick, dark or light), a blistering phenotypet, the surface involved (localized or diffuse), the age of onset *(-neonatal*: collodion baby?, Harlequin fetus phenotype?, lamellar ichtyosis, bullous or non bullous ichtyosiform erythroderma, other ichtyosiform manifestations?; *-or not neonatal*), the association with marked inflammation (erythroderma or not), hair (hair defect (alopecia?, hair shaft defect?) or nails abnormalities, the association with predominant extra cutaneous manifestations (neurological symptoms, growth failure, photophobia, keratitis, deafness…), the family history, the existence (or not) of consanguinity, are essential to define as soon as possible the best management. At the end of this first clinical step it's often possible to classify the patient in non-syndromic, or syndromic ichthyosis. But the clinical phenotype may be variable through the life, particularly in the first years of life. The congenital non-bullous ichtyosiform erythroderma (NBIE) and the lamellar ichtyosis (LI) are particularly difficult to be classified. Indeed these cutaneous phenotypes can be observed in non-syndromic, and syndromic inherited ichtyosis. The non syndromic forms are the most frequent, autosomal recessive in most cases. Some authors consider now only the term of lamellar ichtyosis, as NBIE and LI could belong to a same clinical spectrum with: -large, dark and plate-like scales over most of the skin in LI (at a polar end of the spectrum), and -prominent diffuse erythroderma with diffuse fine white scales in NBIE (at the other polar end of the spectrum). Many patients exhibit intermediates phenotypes, and changes with overlapping features can be observed in a same patient over time. So the clinical features observed at a medical visit, are often not sufficient to define a precise subtype of congenital non-bullous

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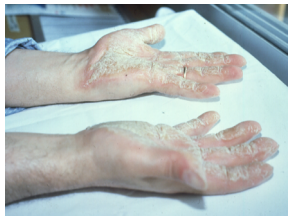
[3] MAGEC, Centre Référence Maladies Génétiques à Expression Cutanée, Service de Dermatologie, Necker-Enfants Malades, Paris, France

ichtyosis. Moreover overlapping genotypes have now been described among the 2 clinical subtypes. Thus, it might be better to consider NBIE and LI as "a variation of a single but closely related group of disorders".
So we can understand that if inherited ichthyoses have been initially classified by clinical features and inheritance patterns, the better understanding of the pathophysiology, and the elucidation of the molecular mechanisms would permit a better classification of these genetic disorders and a better management.

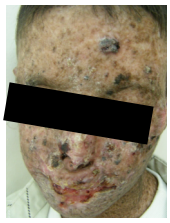
Plamoplantar keratoderma



Hereditary palmopantar keratoderma and Meleda syndrome are characterized by the appearance of patches of hard skin on the feet and on the hands.
Treatment aims at cleaning out patches of hard skin.
Without treatment, the skin on the hands and the feet acquire a horny texture making movement extremely difficult.

Xeroderma pigmentosum

Mohamed Zghal[4] *(translated from French)*



Xeroderma Pigmentosum (XP) is a disabling inherited skin disease characterized by an extreme sensivity of the eyes and the skin to the sun's ultraviolet rays. XP is sometimes combined with neurological disorders.
The diagnosis is clinical and it is based on a persistent erythema and a photophobia from the first months. Pigmentosum spots appear gradually and constantly evolve leading to a characteristic poikiloderma like aspect. From infancy, patients with XP develop benign and malignant skin tumours.
There are 3 clinical forms: the severe one, the mild one, and the variant one. The earliness of the appearance of carcinomas and melanomas depend on the severity of the clinical form. These skin cancers condition the functional and vital prognosis of the disease.
On the molecular level, this pathology is characterized by a defect repair of the ultraviolet light damages of the ADN. The ADN repair capacity thanks to the "nucleotide excision repair" (NER) system is measurable with the autoradiography technology in "unscheduled DNA-synthesis" (UDS). This technology allows early laboratory diagnosis and prenatal diagnosis.
In addition to the variant XP, seven genetic types of XP (classified from A to G) have been identified. The genes and the different mutations have been cloned and located.
The care of XP patients is difficult and expensive. It requires collaboration between specialties. Management is mainly based on prevention, early diagnosis, drastic photo protection (living daily life at night), detection and treatment of every sign of cancer. Treatment of skin cancer for XP patients is the same as the one for patients without XP. Surgery, cryosurgery and chemotherapy are the most used. But, radiotherapy must be avoided because of the high risk of radiation-induced carcinoma for XP patients.

Other genodermatoses
This working group focuses on 8 groups of diseases:
- Anhydrotic ectodermal dysplasia and incontinentia pigmenti
- Neurofibromatosis
- Cutis laxa
- Genotrichoses
- Tuberous sclerosis

[4] Dept of Dermatology, Hôpital Habib Thameur, Tunis, Tunisia

- Melanocytic disorders
- Trichothiodystrophy
- Ehlers Danlos syndrome

PARTNERS, PATRONS AND SPONSORS

Fondation René Touraine

Fondation René Touraine is a state recognized and a non-profit organization. It aims at improving dermatology care by getting together the stakeholders of therapeutic advances. Through the development of an international network for the management of severe genodermatoses and by backing up requests to governments and health authorities, Fondation René Touraine aims at supporting and encouraging local initiatives to help patients and families.

Laboratoires Pierre Fabre

Laboratoires Pierre Fabre is a French pharmaceutical and cosmetics company. Laboratoires Pierre Fabre is well known for its ethical approach of dermatology therapeutics. They make this initiative possible by sponsoring coordination office since 2003 and by supporting international meetings.

Societies of Dermatology and Societies of Pediatric Dermatology

The Societies of Dermatology and the societies of Pediatric Dermatology -when they exist- in Algeria, Bahrain, Croatia, Cyprus, Egypt, France, Greece, Iran, Iraq, Israel, Italy, Jordan, Kuwait, Lebanon, Libya, Malta, Morocco, Oman, Palestinian Territories, Portugal, Saudi Arabia, Syria, Spain, Tunisia, Turkey, United Arab Emirates, Yemen, have been asked for identifying dermatologists and other specialists (geneticists, pediatricians, public health officials, etc.) interested in working to improve the health care and social support for patients and families suffering from severe genodermatoses.
Dermatologists set up the project, on a voluntary basis, according to the goals and an agenda appropriate to the health and social situation/organization in each country.
The Societies of Dermatology and the Societies of Pediatric Dermatology host the yearly working session (2005: Lebanese Society of Dermatology, 2006: Tunisian Society of Dermatology, 2007: Alexandria (Egypt) Society of Dermatology).
The Pan Arab League of Dermatologists supports the project.

Ministries of Health and Research

The Algerian, Croatian, Egyptian, French, Greek, Iranian, Italian, Moroccan, Saudi Arabian, Tunisian, Yemeni ministers of health delivered a speech or gave their high patronage for one or more yearly working sessions.
The Tunisian Minister of Research gave his high patronage for the 2006 working session organized in Tunisia.

French Ministry of Foreign Affairs

The French Ministry of Foreign Affairs through the embassies and the Paris headquarters has supported in 2005, 2006 and 2007 the participation of specialists of partner countries by sponsoring their travel or their accommodation.

Leem

The Leem, the organization of French pharmaceutical companies has supported in 2006 and in 2007 the working sessions. In addition, the Leem participates in an initiative to improve the access to drugs and medical devices for patients affected by severe genodermatoses.

Regional Organizations

The World Health Organization Mediterranean Centre for Vulnerability Reduction (WMC) supported the 2006 meeting in Tunisia.
The General Secretary of the League of Arab States gave his high patronage to the 2007 working session organized in Alexandria.

Orphanet

Orphanet, the free-access website providing information on rare diseases and orphan drugs, supports "Genodermatoses and Mediterranean" since the beginning. Orphanet hosts www.genodermatoses-et-mediterranee.org

Associations of patients and civil society

The associations of patients are invited to participate in the working sessions and are regularly informed of the project.
Les "Enfants de la Lune", the French Xeroderma Pigmentosum Association of Patients, because of their links with the Mediterranean region, is particularly involved in "Genodermatoses and Mediterranean".
In addition, the development or the setting up of associations of patients is promoted in each partner country.

MILESTONES

2003 Forum on Sustainable Development

November 27-29, Paris, France.
Participating countries: Algeria, France, and Tunisia.
> Launching of « Genodermatoses and Mediterranean »

2004 Euromed Forum on Health

February 14-15, Algiers, Algeria.
Participating countries: Algeria, France, Lebanon, Malta, Morocco, Tunisia.
> Determining actions to be set up in each country and to be developed on the international level

2005 Working Session

May 26-27, Beirut, Lebanon.
Under the high patronage of the Algerian, French, Iranian, Italian, Moroccan, Tunisian ministers of health and the Tunisian minister of research.

Participating countries: Algeria, Egypt, France, Greece, Iraq, Iran, Italy, Lebanon, Libya, Morocco, Oman, Palestinian Territories, Tunisia.
> Presentation of the situation of the patients in each country and proposition of solutions to improve health and social care.

2006 Working session

May 26-27, Tunis, Tunisia.
Genodermatoses: a severe skin handicap.
Under the high patronage of the Algerian, French, Greek, Moroccan, Tunisian ministers of health.
With the support of Leem (Organization of the French Pharmaceutical companies), WMC (World Health Organization Mediterranean Centre for Vulnerability Reduction).
Participating countries: Algeria, Egypt, France, Croatia, Greece, Italy, Lebanon, Morocco, Oman, Palestinian Territories, Tunisia.
> Description of a strategy for the integration of genodermatoses in the field of public health issues such as chronic diseases, rare diseases, handicap, skin diseases.

Other international meetings

"Genodermatoses and Mediterranean" initiative has been discussed in:
- PALD 2004, Pan Arab League of Dermatologists, May 31-June 3, Marrakech, Morocco.
- EADV 2004, European Academy of Dermatology & Venereology, November 17, Firenze, Italia
- AMED 2004, Association Méditerranéenne de Dermatologie, June 25-26, Montpellier, France

2007 WORKING SESSION

In brief

Each year, a working session gets together the partners in the project. The 2007 working session took place in Alexandria on April 27 and 28, organized in partnership with the Alexandria Society of Dermatology and the co-coordinator of "Genodermatoses and Mediterranean" in Egypt, Dr. El-Gamal.

The 2007 working session was under the high patronage of Mr. Amr Moussa, General Secretary of the League of Arab States; Mr. Hatem El Gabaly, Minister of Health and Population, Egypt; Mr. Adel Labib, Governor of Alexandria; Mr. Philippe Bas, Minister of Health and Solidarity, France; Mr. Mohamed-Cheikh Biadillah, Minister of Health, Morocco; M. Amar Tou, Minister of Health, Population and Hospital Reform, Algeria; Mr. Mohamed Ridha Kechrid, Minister of Public Health, Tunisia; Mr. Abdul Kareem Rasee, Minister of Health and Population, Yemen; Mr. Hamad Bin Abdullah Almanee, Minister of Health, Saudi Arabia.

The working session was supported by the Laboratoires Pierre Fabre, the Ministry of Foreign Affairs, France; Les Entreprises du Médicament (Leem), France; the Ministries of Health of Algeria, Morocco, Saudi Arabia, Tunisia and Yemen.

This working session got together the representatives of 11 partner countries (Algeria, Croatia, Egypt, France, Greece, Libya, Morocco, Saudi Arabia, Tunisia, Turkey, Yemen) with the

involvement of 2 new partners countries: Saudi Arabia and Turkey. Cyprus, although not in Alexandria, joined "Genodermatoses and Mediterranean" in 2007.

This working session got together dermatologists, geneticists, pediatricians, representatives of patients and civil society, public health officials.

2007 achievements

Involvement of 3 new partner countries:
- Cyprus,
- Saudi Arabia,
- Turkey.

Involvement of new partners in each country and stepping up of the efforts towards national network:
- In Egypt with the development of an extensive network getting together dermatologists, geneticists, pediatricians, representatives of patients and civil society;
- in Greece with a national network of 3 university clinics (Athens, Ioannina, Thessaloniki);
- in Tunisia with the involvement of additional experts.

Organization of 5 international and multidisciplinary taskforces on 5 groups of pathologies:
- Epidermolysis bullosa,
- severe ichthyosis,
- plamoplantar keratoderma,
- xeroderma pigmentosum and DNA damage diseases,
- other severe genodermatoses (anhydrotic ectodermal dysplasia and incontinentia pigmenti, neurofibromatosis, cutis laxa, genotrichoses, tuberous sclerosis, melanocytic disorders, trichothiodystrophy, Ehlers Danlos syndrome).

Finalization of proposals for a co-funding of the European Union in the field of:
- Public heath,
- research.

Social and health care training for medical and paramedical staff and for families:
- Training of Algerian and Egyptian specialists in referral centers for genodermatoses, training of paramedics in France;
- education of medical students and doctors, other health workers, patients and families, general public, policy makers in Libya;
- training session for medical doctors, dedicated subjects in dermatology and pediatric dermatology congress and specific training for caregivers in Tunisia.

Support of the Ministries of Health:
- Special budget dedicated to the drugs for genodermatoses in the 2 main hospitals of Algiers, Algeria;
- patronage and support to travel and accommodation of participants from the Ministries of Health of Algeria, Morocco, Saudi Arabia and Yemen.

Efficient collaboration with association of patients and civil society:
- DEBRA centre in Croatia;
- evidence-based protocol on the French EBAE website;

- support of the medical community to the creation of a non-profit organization for epidermolysis bullosa children in Egypt, participation of Caritas Egypt.

New referral centers for genodermatoses:
- The Shark Al Medina Hospital in Alexandria, Egypt;
- the reference centre in Genodermy in Athens University;
- the genodermatoses units of the pediatric dermatology clinic in Tripoli and in Benghazi (Libya);
- the Pediatric Dermatology Clinics in Tunis (Tunisia).

Multidisciplinary approach reinforced in:
- France,
- Egypt.

Development of medical and paramedical pluridisciplinary working groups:
- in France (epidermolysis bullosa, incontinentia pigmenti, anhydrotic ectodermal dysplasia, Cutis Laxa, ichthyosis).

Database:
- CEMARA (CEntre MAladies RAres database) in France.

Guidelines:
- Detailed medical/history guidelines for the most common genodermatoses in Greece (ichthyosis, epidermolysis bullosa, neurofibromatosis, palmoplantar keratoderma);
- French xeroderma pigmentosum guidelines.

Integration of genodermatoses in the field of major public health issues:
- Rare diseases in Algeria;
- skin diseases in Morocco;
- handicap in Egypt and Tunisia;
- genetic diseases in France (IMAGINE)

Actions to raise awareness of officials:
- Free sterile dressing for epidermolysis bullosa patients in Sfax, Tunisia,
- air conditioning for anhydrotic ectodermal dysplasia patients in Tunis, Tunisia.

Research:
- French and Algerian collaboration on keratinisation disorders and mainly on ichthyosis (7 genes identified);
- Cutis laxa group in France: molecular and histological aspects, dynamic skin reconstruction;
- Creation of research team focused on genodermatoses in Tunisia

2007-2008 goals

Partner countries have decided to focus on the development of good practices, the health care community networks, the access to drugs and medical devices.
The 2008 working session will be held in Rabat (Morocco) on June 6-7.

SUMMARY OF THE SITUATION IN THE PARTNER COUNTRIES PARTICIPATING IN THE 2007 WORKING SESSION

Algeria

Bakar Bouadjar[5], Ismail Benkaidali[6]

2006-2007 epidemiological data

Xeroderma Pigmentosum: 370 cases, 90 families ; Recessive Ichthyosis: 200 cases, 120 families ; Mal de Meleda: 60 cases, 35 families ; Hereditary Epidermolysis bullosa: 100 cases, 60 families ; Familial Psoriasis: 80 cases, 70 families ; Familial Vitiligo: 40 cases, 20 families ; Tuberous Sclerosis of Bourneville: 28 cases, 10 families

- Epidermodysplasia verruciformis: 24 cases, 20 families
- Others: Kindler syndrome, Papillon-Lefèvre Syndrome, Chanarin Dorfamn Syndrome

French-Algerian cooperation for training in the field of health and social cares

- Training of an assistant from the department of dermatology of Bab El Oued Hospital in the unit of Pediatric Dermatology in Pellegrin Enfants-Malades Hospital in Bordeaux (France)
- Talk in Algeria of a social worker from MAGEC, Necker- Enfants Malades Paris (France), about social care in genodermatoses
- Training of an hospital attendant from the department of dermatology of Mustapha Hospital in MAGEC, Necker- Enfants-Malades, Paris (France) to learn special care of Epidermolysis Bullosa.

More than €200 000 from the Ministry of Health for drugs

About 2 milliards of dinars (about € 20 millions) have been given for prevalent orphan diseases among them genodermatoses (DA 19 565 000 = € 207 867).

This budget is given to the directors of the 2 main hospitals of Algiers to buy drugs. This budget will be renewable each year with a possibility to increase this amount if necessary.

	Number of cases	**Dinars**	**Euros**
Xeroderma pigmentosum	200	5 720 000	60 772
Ichthyosis	220	12 320 000	130 893
Palmo-plantar keratoderma	150	1 400 000	14 874
Hereditary Epidermolysis bullosa	50	125 000	1 329
Total	620	19 565 000	207 867

Associations of patients

- The associations of patients with psoriasis created in 2006 under the scientific patronage of Prof. I. Benkaidali and B. Bouadjar expands.
- On the new Website of the Algerian Society of Pediatric Dermatology a rubric is dedicated to patients and families.
- An effort is done to build a Website where patients with rare diseases could be informed and express themselves.

A conference on orphan diseases

A conference on orphan diseases is in preparation in Health Ministry. It will get together all the stakeholders involved in this category of chronic diseases.

The Ministry of Work and Social Affairs will be represented. The discussion will focus on which orphan diseases could be integrated in the category of chronic diseases.

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[5] President of the Algerian Society of Dermatology, Dept. of Dermatology, C.H.U. Mustapha, Algiers, Algeria

[6] President of the Algerian Society of Pediatric Dermatology, Dept. of Dermatology, CHU of Bab-El-Oued, Algiers, Algeria

Research
Collaboration with Judith Fischer, Centre National de Génétique in Evry (France) in keratinisation disorders and mainly on ichthyosis (7 genes identified).

Croatia

Mihael Skerlev[7], A. Stanimirović[6], S. Murat-Susić[6], K. Husar[6]

The joint achievements of the Croatian Debra team and the Department of Dermatology and Venereology of the University Hospital and Medical School of Zagreb

- 10 years of DEBRA Croatia, sponsored by the "Opening Society Institute" and "Partnership beyond borders". Gathered 110 participants from 12 countries.
- New Debra Center with accommodation facilities for visiting families, a medical room, a meeting room...
- New booklets for the care of patients with epidermolysis bullosa (Nutrition for patients older than one year, Physiotherapy, Information about the disease), printing in Croatian of *The boy who dared*, an illustrated children's book dedicated to EB sufferers
- Visit to Debra Slovenia to meet with parents and professionals
- Visit and surgery for patients with epidermolysis bullosa in Bosnia, Serbia, Montenegro, Macedonia
- Splints for epidermolysis bullosa patients in Slovenia
- Visit to DEBRA center of Dr Asis Khan from Cincinnati Hospital

Egypt

E. El-Gamal[8]
M.A. Abdallah[9], Mahira El Sayed, Taymour Khalifa, Mohammad El Darouty, Abdallah Kato[10], Suzan Roshdy Ismail[11], Ghada El Kamah[12], Adel Botros Zaghloul[13], Ahmed Kamal Hassan[14], Hanah El-Sadat[15], M. El Sawy, Sany Kouzman, Amal Eweiss, Youssef Wahba Aziz[16]

2 referral centers for genodermatoses in Egypt

The genodermatoses clinics in El-Haud El Marsoud Hospital, Cairo, is, since 2006, a referral center for rare inherited disorders requiring special tests and multidisciplinary management, for dysmorphic syndromes, for high risk pregnancies, abnormal fetus stillbirth (to be investigated in cooperation with perinatal pathologist), genetics laboratory to assess risks for future pregnancies.

- Mission: to organize databases and registries (ages/sex, geographic data, diseases, follow-up); to promote population awareness; to train physicians, nurses, social workers; to inform families with an inborn child; to provide counseling; to diagnose; to provide a multidisciplinary team approach.
- Goals: to improve diagnosis and management, to become a referral center for Egypt, to organize a national registry and to develop cooperation with other centers and abroad.

The Shark Al Medina Hospital, Alexandria, one of the biggest hospitals in Alexandria is a referral center for patients with genodermatoses since 2007.

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[11] Human Genetics Department, MRI, Alexandria University, Egypt
[12] National Research Center, Egypt
[13] Clinic Director, El Haud El Marsoud Hospital, Egypt
[14] Hospital Director, El Haud El Marsoud Hospital, Egypt
[15] Mother of a ten year old epidermolysis bullosa child, Egypt
[16] Caritas Egypt - Alexandria

Multidisciplinary teams from all Egypt
Involvement of specialists from all over Egypt (2005 working session: 1 participant, 2006 working session: 4 participants, 2007 working session: large and various delegation with dermatologists, geneticist, representative from Caritas-Alexandria[17], the mother of a 10 year old epidermolysis bullosa patient)

International cooperation and interaction
Clinical director of the genodermatoses clinics of El Haud El Marsoud Hospital spent a month in the genodermatoses clinic in St Louis Hospital (Paris, France), lecture in Beaumon Hospital (Lausanne, Switzerland).

Towards a non profit organization for epidermolysis bullosa children in Egypt
Mrs. El-Sadat handles 11 epidermolysis bullosa cases by teaching parents how to deal with epidermolysis bullosa (bandage, prevention of blisters, treatment of infection, guidelines for nutrition, vaccination, surgical treatment, frequent dental care) and by giving them supplies.
The following activities are in preparation:
- Translation of DEBRA booklets in Arabic,
- Creation of a non profit organization for epidermolysis bullosa children in Egypt to collect donations and cover health care costs,
- Signature of a protocol between the non-profit organization for epidermolysis bullosa children in Egypt and El Haud El Marsoud Hospital.

2006 skin disorders at the Human Genetics Department, MRI, University of Alexandria in 10 000 cases: Xeroderma pigmentosum: 7; Epidermolysis bullosa: 15; Ichthyosis: 14; Erythema keratoderma: 2; Ectodermal dysplasia: 6; Tuberous sclerosis: 8; Psoriasis: 1; Neurofibromatosis: 6; Incontinentia pigmenti: 1; Other skin disorders: 10.

France

S. Hadj-Rabia[18], C. Bodemer[18]

MAGEC, a national multi-sites reference center with a patient-centered approach
- Necker Enfants Malades Hospital, Sein Louis Hospital, Avicenne Hospital,
- Professionals, projects, tools and structures are focused on the needs of the patients.

MAGEC team
2006: 3 permanent physicians with different specificities
- Clinical and therapeutic expertise: C. Bodemer
- Molecular genetics and genetic counseling: S. Hadj-Rabia
- Epidemiology: E. Bourdon-Lanoy
- Coordination desk: K. Ausset-Delon
- Social worker: H. Dufresne
- Anatomopathologist technician

2007: + 3
- Psychological research: S. Jacob
- Nurse and therapeutic education: I. Corset
- Technician (hospital molecular genetics): close relation with hospital genetic department

[17] Caritas -Alexandria is a very active Non Governmental Organization in Egypt
[18] MAGEC, Centre Référence Maladies Génétiques à Expression Cutanée, Service de Dermatologie, Necker-Enfants Malades, Paris, France

MAGEC Patients

Multidisciplinary care

Medical, social (school, resting centers, "hospitalization at home", integrascol[19], education of patients, education of the local and community-based teams, week-end for therapeutic education, psychologist for patients and their family).

Difficulties: resting centers for patients and their families, specific room for education skin care

Medical and paramedical pluridisciplinary working groups (2006)

Epidermolysis bullosa group:

- dermatologists, pediatricians, anaesthetits, nurses, physical therapist,
- "protocoles de soins" (evidence-based protocols) on EBAE and MAGEC Websites.

Cutis laxa group:

- molecular and histological aspects,
- dynamic skin reconstruction through an INSERM[20]-MAGEC-NEM[21] collaboration thanks to an AFM[22] grant.

Ectodermal dysplasia group:

- dermatology, NET, pneumonology, ophthalmology, molecular group supported by grants

Incontinentia pigmenti group:

- radiology, neurology, ophtalmology,
- molecular group.

Xeroderma pigmentosum group:

- French guidelines (Haute Autorité de la Santé, Ministry of Health).
- No French group for molecular research.

Under process:

- Ichthyosis and keratinisation disorders research network but no clinical network.
- Tuberous sclerosis of Bourneville (collaboration with neurological center of reference).
- Hereditary Epidermolysis Bullosa and anhydrotic ectodermal dysplasia: French guidelines (Haute Autorité de la Santé, Ministry of Health).

MAGEC Tools

2006: CEMARA (CEntre MAladies RAres database) is under construction. CEMARA is an epidemiological database developed through a collaborative network.

What's next? A website in connection with families' associations' websites

MAGEC Network

- **France**: Inserm, Interaction with other centers of reference for genetic skin diseases, IMAGINE Center (Institut des MAladies GéNétIquEs) is dedicated to research, cellular and molecular therapy. IMAGINE is one of the top priority of Necker-Enfants Malades campus. Inclusion of genodermatoses in IMAGINE.
- **Europe**: Therapeuskin and Geneskin
- **International**: Genodermatoses and Mediterranean

[19] Integrascol is a joint Programme from the Ministry of National Education, the Ministry of Health, and the "Secretariat d'état" for Handicapped persons under the patronage of the Academy of Medicine. Integrascol promotes and eases the integration into school of children with chronic or severe diseases or handicap. www.integrascol.fr

[20] Inserm is the only French public organization entirely dedicated to biological, medical and public health research.

[21] Necker Enfants Malades Hospital.

[22] Association Française contre les Myopathies, French Muscular Dystrophy Association.

Greece

Alexandra Katsarou[23]

A reference center in Genodermy in Athens University.

A national network of 3 university clinics: Athens, Ioannina, Thessaloniki.
Epidemiological data (results from 3 university clinics in Athens and of Salonica) of 142 367 patients, from April 2006 to March 2007
Ichthyosis: 21; Dariers' Diseases+ Hailey-Hailey: 15 ; Porokeratoses: 9; Neurofibromatoses: 6 Palmoplantar Keratoderma: 9; Epidermolysis bullosa: 4; Naxos disease: 3; Eythrokeratoderma: 2; Tuberous Sclerosis: 2; Xeroderma Pigmentosum: 2; Incontinentia Pigmenti: 2; Netherton's Syndrome: 1.

Detailed medical history guidelines for the most common genodermatoses in Greece
- Ichthyosis, epidermolysis bullosa, neurofibromatosis, palmoplantar keratoderma
- For a better and easier diagnosis. These medical guidelines have been used in every center of the Greek network

Libya

Abdelaziz Alahlafi[24]*, Mariam Bozgia*[25]*, Gamal Duweb*[24]

Genodermatoses units in Pediatric dermatology clinic in Tripoli and in Benghazi in 2006
Registry, Expertise, Scientific collaboration, Social collaboration, Training to improve diagnosis, Improving lab facilities, Involvement of social workers, Education of medical students and doctors, other health workers, patients and families, general public, policy makers.

Genodermatoses in Benghazi city
37 patients from 5 to 62 years: 24% Darier's disease (9 cases/2 families); 29% epidermolysis bullosa (11 cases/2 families); 13% xeroderma pigmentosum (5 cases/2 families); 8 % tuberous sclerosis (3 cases); 8% Ichthyosis (3 cases); 1 neurofibromatosis; 1 tylosis; 1 progeria; 1 pachydermoperiostosis; 1 focal dermal hypoplasia; 1 Wiskott Aldrich syndrome.

Morocco

A. Idrissi Azzouzi[26]

Towards a global and integrated public health strategy for skin diseases
- In 2007 focus on the review of the local organization partnership with a meeting gathering health authority, dermatologists, primary health care workers, social workers, information and communication specialists. The network will be organized as follow: national referral centers (1 national center for leprosy, 4 national referral centers for dermatology), regional referral centers (skin diseases services), Primary health care / Families / Communities.
- Implementation of the strategy: Fight leprosy, a practical guide for health professionals, 2007 (Moroccan Ministry of Health and WHO)

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[23] Dept. of Dermatology, University of Athens, Greece.
[24] Faculty of Medicine, Omar Al-Mukhtar University, Al-Baida City, Libya
[25] Dept of Dermatology, Faculty of Medicine, Garyonis University, Benghazi, Libya
[26] Ministère de la Santé, Division des maladies transmissibles (DMT), Direction de l'Epidémiologie et de la lutte contre les maladies (DELM), Rabat, Morocco

Strategy for genodermatoses in Morocco

- To sustain and coordinate centers dedicated to genodermatoses (network: primary health care and dermatologists, multidisciplinary team)
- To improve social support for patients affected by genodermatoses
- To develop expertise in Genodermatoses
- To implement the genodermatoses strategy:
  - Define norms and procedures for the management according to local context
  - Develop and strengthen networks
  - Get funding

Saudi Arabia

Khalid Al Aboud[27]

Genetic disorders are a public health issue

Many efforts are done by governmental and non-governmental organizations to control genetic disorders through a prevention policy:

- National committee for genetic disorders, Ministry of Health,
- National committee for medical and biological ethics,
- National genetic and birth defects registry, funded by Prince Salman Centre for Disability Research and King Faisal Specialist Hospital and Research Center,
- Referral centers for families with genetic disorders provide advanced services (including pre-implantation genetic testing),
- Saudi Royal Decree: the pre-marital examination is a health preventive measure for all Saudis. The 2 prospective partners (male and female) have to carry out a pre-marital examination and present the certificate before the wedding.

A significant number of families affected by genodermatoses

Genodermatoses are not as common as haemoglobinopathies or inborn errors of metabolism, yet there are significant numbers of families with genodermatoses. A review by Al Aboud, et al in Gulf Journal of Dermatology and Venereology has shown that both common like epidermolysis bullosa and ichthyosis and uncommon genodermatoses like Kindler syndrome and hereditary hypotrichosis are seen in the Kingdom.

Few studies done on genodermatoses in Saudi Arabia have revealed different mutations from those described elsewhere.

Among genodermatoses, blistering disorders occur the most (epidermolysis bullosa is common).

A well developed free medical facilities and well implemented national social policy for handicaps

Ministries, large health care facilities, health care workers, professional societies, NGO, charities are involved in health care and social support (integration, privileges, houses, financial support).

The Saudi Society of Dermatology and Dermatological Surgery plays a good part in helping patients and families.

Towards a regional network for prevention and health care

It is hoped that a network will get together national efforts and regional efforts to provide preventive measures and a better care for patients and families.

[27] Dept. of Dermatology, King Faisal Hospital, Makkah, Saudi Arabia

Tunisia

M.R. Kamoun[28]
M. Kharfi[27], *R. Nouira*[29], *H. Turki*[30], *M. Denguezli*[31], *B. Fazaa*[27], *N. Doss*[32], *R. Dhaoui*[31], *I. Mokhtar*[33], *M. Zghal*[32]

Healthcare

Genodermatoses are a handicap

According to the new law on handicap, genodermatoses are a handicap. So, patients have special rights:

- Free health care in public health facilities,
- Free drugs in hospitals (such as Soriatane in University Hospital),
- Free transportation in city and 50% off inter-city transportation.

Actions to raise awareness

- Free sterile dressing for epidermolysis bullosa patients in Sfax,
- Air conditioning for Anhydrotic ectodermal dysplasia patients in Tunis.

Antenatal diagnosis

Groups of specialists are structuring a network open to all patients

Genetic counseling is available to patients in several university hospitals

In Pediatric Dermatology Clinics in Tunis in Charles Nicolle hospital and in Enfants hospital

A genodermatoses clinics on weekly basis

is scheduled to open soon in Charles Nicolle Hospital, Tunis

A group of specialists for preventive destruction of precancerous lesions for xeroderma patients

Training

- Training session for Medical Doctors with the Society of Medical Sciences and thanks to dedicated subjects in dermatology and pediatric dermatology congress,
- Specific training for caregivers in Sousse (Medical School).

Research

- Increasing interest for genodermatoses in medical teams,
- National studies in process,
- Studies in partnership with France: ichthyosis, acrodermatitis enteropathica,
- Creation of research team focused on genodermatoses: Sousse, Tunis.

Partnership with specialized teams from Europe and mainly from France.

- Exchange of advice about patients (diagnosis, management, transfer of patients when necessary),
- Participation in the French Xeroderma Pigmentosum guidelines.

Towards a multidisciplinary management coordinated through networks?

Health

- Better access to specific drugs,
- Development of specific networks for the management of genodermatoses,
- Development of a network for accessible, reproducible and regular antenatal diagnosis.

[28] Dept of Dermatology, Hôpital Charles Nicolle, Tunis, Tunisia
[29] Ecole Supérieure de Santé, Sousse, Tunisia
[30] Dept of Dermatology, CHU Hédi Chaker, Sfax, Tunisia
[31] Dept of Dermatology, Hôpital Universitaire de Sousse, Tunisia
[32] Dept of Dermatology, Hôpital Militaire, Tunis, Tunisia
[33] Dept of Dermatology, Hôpital Habib Thameur, Tunis, Tunisia

- **Training**
- Structured action for training and information for medical staff,
- Support and develop dedicated training for caregivers,
- Information and formation for parents about management and prevention.

Associations of patients

- Project of creation of an association of patients but difficulties to get required authorization.

National network

- Government: health, education, children, handicap authorities,
- Civil societies organizations involved in solidarity, vulnerability reeducation, human rights,
- Various specialties: dermatologists, pediatrician, geneticist, obstetricians, biologists, plastic surgeons, radiotherapist…
- Between medical doctors and scientists.

International partnership:

- Between countries (South- South / North- South)
- With international organizations involved in health and handicap (WHO, UNICEF)
- With private sector (foundations, pharmaceutics companies….)

Guidelines

Turkey

Rana Anadolu Brasie[34]

Who is taking care of the genodermatoses?

Dermatologists, Pediatricians, Biogeneticist, Family practitioners, Ministry of health through preventive healthcare and prenatal diagnosis units.

Who is taking care of health costs related to genodermatoses?

There is no single healthcare-social security umbrella. Patients usually belong to poor socio-economical status and live in under developed rural areas with limited health care facilities.

The most common genodermatoses in Turkey

Summary *(Turkderm 2006; 40: 133-5)*

Genodermatoses, have a significant place in the skin diseases, involving more than 200 diseases. There is no significant study in frequency and abundance of genodermatoses in Turkey. In this study, we tried to emphasize the frequency and abundance of genodermatoses with a high number of cases.

- Materials and Methods: We detected 1303 records of cases, which were diagnosed to have a genodermatose among 400.000 cases who admitted to our outpatient service or hospitalized in our department between 1981-2005.
- Results: Among 400.000 cases, these 1303 cases have an occurrence rate of 0.325% diseases, localized palmoplantar keratoderma 232 (17.8%), ichthyosis vulgaris 201 (15.4%), epidermolysis bullosa 175 (13.4%), neurofibromatosis 97 (7.4%), ichthyosis lamellaris 91 (6.9%), Darier's disease 66 (5.1%), Klippel-Trenaunay syndrome 46 (3.5%), xeroderma pigmentosum 44 (3.4%), oculocutaneous albinism 35 (2.6 %) and ectodermal dysplasia 29 (2.2%) are the ten most frequent ones. If the first 5 of these genodermatoses are evaluated on a geographical basis, the highest numbers of the cases are from South Eastern Anatolia, with Inner Anatolia and Black sea regions following it. In Marmara and Aegean regions, the number of genodermatoses is lower. High prevalence of genodermatoses in South East and Inner Anatolian regions suggests that there are more kin-marriages in these regions.

[34] Ankara University Medical School, Ibni-Sina Hospital, Turkey

A governmental public health issue

- Turkish government launched a public campaign towards increasing awareness of genetic diseases and risk of consanguine marriages.
- Pre-marital counseling is being offered to young couples.
- Nevertheless, the problem of genetic disorders in general and genodermatoses in particular is still there.

Turkey is freshly joining the Mediterranean Genodermatoses Group

Prevention is easier to achieve than management:

- Public education to increase the awareness,
- Pre-marital counseling,
- Pre-natal diagnosis,
- Wider social security umbrella for the affected individuals and families.

Yemen

Dr. Abdul Rahim Al Samie[35]*, Dr. Yasin Al Qubati*[36]

A concealed serious health problem of childhood

The most common genodermatoses in Yemen are xeroderma pigmentosum, ichthyosis vulgaris, epidermolysis bullosa, palmoplantar keratoderma, birth nevi.

Action

A dedicated form for data collection used in Skin Veneral Disease Hospital in Madinat Al Noor Taiz: Ichthyosis vulgaris: 16; Palmoplantar keratoderma: 7; Epidermolysis bullosa: 2

Proposed solution to improve health care and social support

- To set up a national network for care
- To develop an information system: national registry, collect of information, information to physicians
- To link the problem in Yemen to international and regional project to get support
- To target 5 genodermatoses: epidermolysis bullosa, ichthyosis vulgaris, palmoplantar keratoderma and Meleda Syndrome, xeroderma pigmentosum, birth nevi before complication

On the agenda

- Improve the quality of care in the field of general services center, specialized centers, diagnosis procedures,
- Improve patient support (international: information, training, drugs; local: Skin and Venereal Diseases Hospital, Taiz),
- Promote the communication, information and training (informational websites, educational brochures),
- Support research (on the national level, establishment of a co-operative project in the private and public sectors),
- Reinforce ties (with Minister of Social Affairs, Higher Education and Research, Universities, NGO, International Organization, patients' families through an association).

[35] Skin and Venereal Diseases Hospital, Taiz National Leprosy Control Program, Yemen
[36] Dept. of Dermatology, Medical College, Taiz University, Yemen

2007 working groups
May 2007

Epidermolysis bullosa

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> Report

The working group plans to tackle problems, promote ideas or contribute with their special experience to the life of EB sufferers will focus on:

- Build a platform for people with an interest in a certain area of our discipline,
- Build a bridge in between existing EB societies in different parts of the world,
- Contribute in the preparation of guidelines,
- Be the contact to lay social organizations in the Mediterranean countries,
- Make proposals for themes and possible speakers to the scientific activities,
- Be a nucleus for EB research projects.

Severe ichthyosis

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> Report

In progress...Coming soon at www.genodermatoses-et-mediterranee.org

Palmoplantar keratoderma

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> Report

In progress...Coming soon at www.genodermatoses-et-mediterranee.org

Xeroderma pigmentosum and DNA damage diseases

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> Report

The 1st working session of the xeroderma pigmentosum working group focused on discussing the methodology to set up guidelines:

- Description of a methodology,
- Discussion of goals,
- Identification of the stakeholders of the health and social care,
- Integration of this pathology in the public health national programmes,
- Exchanges of experiences and identification of the centers of reference in each country.

1. Goals

- Strategy for early screening of xeroderma pigmentosum,
- Set up means of actions for early diagnosis and for slowing down the development of the disease,
- Make the most, for patients, to prevent and treat skin cancers,
- Strengthen collaboration with the other specialists of the health and social care,
- Organize facilities for social support,
- Carry out a Mediterranean cartography of xeroderma pigmentosum,

- Strengthen scientific programmes about the development of tools for fast and early diagnosis, prevention, curative treatment and gene therapy.

2. Identification of the stakeholders of the health and social care
- 1st row physicians: family doctors, paediatricians,
- Dermatologists,
- Other specialities: ophthalmologists, neurologists, psychiatrists, geneticists,
- Cancer specialists: surgeons, chemotherapy specialists, radiotherapists,
- Doctors in charge of the national programmes of public health,
- Paramedics,
- Social workers,
- Parents.

3. Documents
- Bibliography,
- EMC,
- Dermatology in general medicine, Fitzpatrick & coll.,
- The genetic basis of human cancer. Nucleotide excision repair syndromes: xeroderma pigmentosum, Cockayne syndrome and trichothiodystrophy. New York: McGraw-Hill Bootsma D, Kraemer KH, Cleaver JE. In: Vogestein B, Kizler KW, editors,
- Haute autorité de santé (www.has-sante.fr): Xeroderma pigmentosum, protocole national de diagnostic et de soins pour une maladie rare[37],
- XP support associations.

4. Methodology

Each member, according to the features and the means of her/his country, will propose a plan of action with goals. He can get support from a local committee composed by the experts of health and social care. Taking into account propositions of the different members, the coordinators will present the 1st version of the guidelines. This version will be updated according to the comments of the members and will be adapted to each country

Other genodermatoses

This task force will meet at the next working sessions.

Anhydrotic ectodermal dysplasia and incontinentia pigmenti

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Neurofibromatosis

Coordinators

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[37] French National Authority for Health: xeroderma pigmentosum, national protocol for diagnosis and health care for a rare diseases

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2007 partners' directory
May 2007

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