

TAG
Together Against Genodermatoses

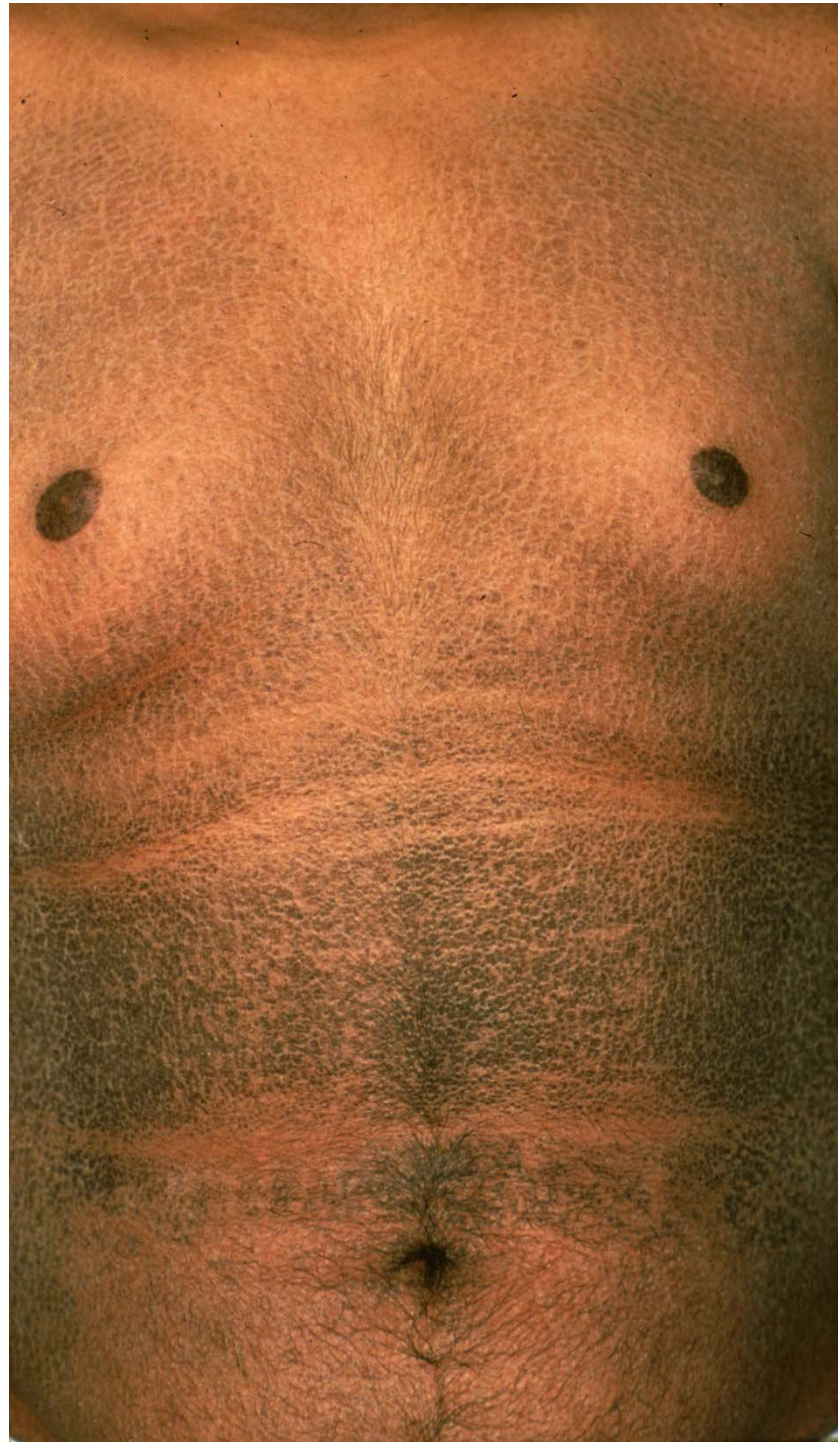
www.tag-eu.org



**Together to improve
the access to cares
and
the quality of management
of
severe genetic skin diseases**

















COORDINATING CENTER

**THE FONDATION RENE TOURAINE FOR
DERMATOLOGY**

A NOT PROFIT EUROPEAN ORGANIZATION

AIMING TO CREATE AND ANIMATE NETWORKS

IN ORDER TO IMPROVE

ACCESS TO SKIN CARE AND SKIN CARE QUALITY



TAG partner countries

EU associate partners

- . Cyprus
- . France
- . Greece
- . Italy
- . Portugal
- . Romania
- . Slovenia

EU collaborating experts

- . Austria
- . Belgium
- . Bulgaria
- . Czeck Republic
- . Germany
- . Hungary
- . Netherlands
- . Spain
- . United Kingdom

Non EU collaborating experts

- . Algeria
- . Croatia
- . Egypt
- . Iran
- . Kuwait
- . Lebanon
- . Libya
- . Morocco
- . Palestinian Territories
- . Russia
- . Saudi Arabia
- . Sudan
- . Syria
- . Tunisia
- . Turkey
- . Yemen

TAG

Together Against Genodermatoses

- Co-funded by the European Commission - TAG n°2007 335
- 48 Partners from European and Non European Countries
- 3 years from Dec.1st, 2008 to Nov. 30 2011
- European Reference Network Pilot Project



TAG goals

- **Better know the needs of patients**
- **Define best prevention strategies**
- **Develop solutions to improve access to drugs and medical services**
- **Promote training of caregivers**
- **Get together the different stakeholders in 3 yearly working sessions**
- **Network specialists, paramedics, associations of patients**
- **Raise public awareness**





International Working Groups

6 diseases working groups



- * Guidelines to improve health care and social support for patients and families suffering from severe genodermatoses
- * Focus on the daily life of patients and families
 - Health care
 - Nursing care
 - Social care
- * Focus on the social and cultural context of each country
- * Connected by internet
- * Meeting once a year

Working Groups Composition



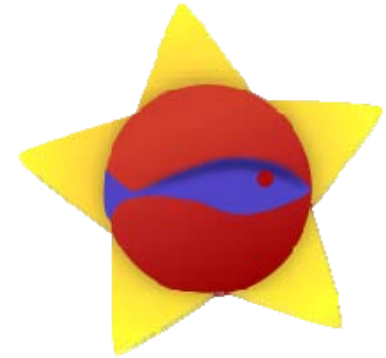
- ▷ Participants:
 - Dermatologists
 - Geneticians
 - Representatives of Patients Associations
 - Nurses
- ▷ Coordination:
 - One non European Union Coordinator
 - One European Union Coordinator

6 diseases working groups



- Epidermolysis Bullosa
- Ichtyosis
- Neurofibromatosis
- Palmoplantar Keratoderma
- Xeroderma Pigmentosum
- Other Genodermatoses: anhydrotic ectodermal dysplasia, incontinentia pigmenti

1 transversal group



Transectional approach of genodermatoses for preventive synergistic actions

Organization of a laboratories network of geneticists dedicated to help patients and families while developing antenatal diagnosis and genetic counselling



TAG achievements

IDENTIFICATION OF THE EXISTING PRACTICES OF SKIN CARE AND OF SPECIFIC KNOW-HOW DEVELOPPED IN EACH SOCIO-CULTURAL AND ECONOMIC ENVIRONMENT FOR EACH GROUP OF GENODERMATOSES

ESTABLISHMENT OF VERY PRACTICAL GUIDELINES FOR EACH GROUP OF GENODERMATOSES

IDENTIFICATION OF THE PATIENTS NEEDS IN TERM OF INFORMATION, CARES, DRUG AND MEDICAL DEVICES SUPPLY IN EACH COUNTRY

IDENTIFICATION OF THE COMPETENCE AND EXPERTISE CENTERS ABLE TO FILL UP THESE NEEDS



TAG achievements

- **CREATION AND TRAINING OF NEW COMPETENCE CENTER**
- **EDUCATION COURSES FOR DERMATOLOGISTS AND NURSES**
- **HELP TO THE DEVELOPMENT OF PATIENTS' ASSOCIATIONS IN EACH COUNTRY**
- **CREATION OF A CLUB OF PHARMACEUTICAL INDUSTRIES INTERESTED TO SUPPLY DRUGS AND DEVICES FOR RARE DISEASES IN DERMATOLOGY**



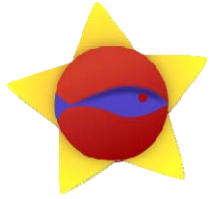
TAG: Future perspectives

- **TO CONTINUE THE SAME STRATEGY, COUNTRY BY COUNTRY, THANKS TO THE STIMULATION AND HELP OFFERED BY AN INTERNATIONAL COLLABORATION**
- **TO ESTABLISH, IN COLLABORATION WITH THE PATIENTS' ASSOCIATIONS, A DIRECTORY GIVING, IN EACH COUNTRY, THE LOCALIZATION AND THE NAME OF THE DERMATOLOGISTS INVOLVED IN THE CARE OF SEVERE GENODERMATOSES AS WELL AS THE NATURE OF AVAILABLE SERVICES (MULTIDISCIPLINARY CONSULTATION, DAY CARE CENTERS, SPECIALISED NURSES, ANTE NATAL DIAGNOSIS, GENETIC CONCELLING, PATIENT EDUCATION.....) AS WELL AS THE STRUCTURE OF THE NETWORK CONCERNING THEIR DISEASE AT THE NATIONAL AND INTERNATIONAL LEVEL.**
- **THIS DIRECTORY WILL BE OPEN FOR THE PATIENTS AND THE G.P.**



TAG: Future perspectives

- **THE AIM OF THIS DIRECTORY IS TO GREATLY FACILITATE THE ACCESS OF THE PATIENTS TO SKIN CARES AND TO STIMULATE, THANKS TO THE INTERNATIONAL COLLABORATION, THE DEVELOPPEMENT OF NEW COMPETENCE AND EXPERTISE CENTERS**
- **THUS WE WANT TO CONTINUE TO CONNECT, TO EDUCATE, TO GATHER ONCE A YEAR THE STAKEHOLDERS OF THIS ACTION (MEDICAL DOCTORS, NURSES, SOCIAL WORKERS, PATIENTS' ASSOCIATIONS, PHARMACEUTICAL INDUSTRIES) AND TO ATTRACT NEW ONES**



A PRACICAL POINT OF MAJOR IMPORTANCE:

The creation and the animation of a network of expertise centres and competence centres is a new full time job for high level non medical persons, experts in networking.

If we look for a long term efficacy, the salary of such key experts have to be paid by the E.U.

