



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

May 22 - May 25, 2009, Greece

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GENODERMATOSES IN MEDITERRANEAN  
IN CROATIA  
IN THE LIGHT OF THE  
INTERNATIONAL NETWORKING

**Vlasta Zmazek**

Debra Croatia  
Croatian Epidermolysis Bullosa Association

# Activities 2008/2009

- Patients advocacy
- Result of Debra SEE project:
  - Treatments for patients older than 18
    - Costs of treatments: out of existing system
  - Debra Bosnia and Herzegovina
  - Debra Serbia

# Ongoing campaign

- Media
- Raise awareness
- Socialization – exhibition, picturebook
- Support



# Education

**The First Regional Symposium on Hereditary Epidermolysis Bullosa, (Mediterranean – Central and Eastern Europe) in Zagreb, Croatia, April 03 04, 2009**

- 14 countries
  - 7 foreign speakers
  - 15 Croatian speakers
- 80 participants
- Organizers
  - Croatian Dermatovenereological Society of the Croatian Medical Association
  - DEBRA Croatia
  - Reference centre for EB of the Ministry of Health and Social Welfare of Republic of Croatia in Univ. Dpt. of Dermatology and Venereology

# Activities: Together – the key word

- EURORDIS
- Debra International
- The Croatian Society of Patients with Rare Diseases
- Coalition of Associations in Healthcare, Croatia
- Genodermatoses



# Towards National Plan for Rare Diseases

- Croatian Society for Rare Diseases of Croatian Medical Association
- 2010 - the First Rare Diseases Conference in Croatia as a part of EUROPLAN