

**Report from TAIEX Workshop for enhancing the Orphanet database for rare diseases,  
Ankara, Turkey July 2-3 2009**

In July 2-3, 2009, a TAIEX (the Technical Assistance and Information Exchange Instrument of the European Commission) Workshop for enhancing the Orphanet database for rare diseases was held in Ankara, Turkey. The workshop venue took place at the Refik Saydam Hygiene Center of the Turkish Ministry of Health. Over 60 participants from the Ministry, University, patient organisations and the biopharmaceutical industry were taking part. The current status of rare diseases and orphan drugs in Europe was presented by Dr. Ségolène Aymé (Director of Orphanet), Dr. Laura Fregonese, Prof. Maurizio Clementi and Dr. Rumen Stefanov. Dr. Krystyna Chrzanowska (Poland) introduced the audience to the network activities of [DYSCERNE](http://www.Dyscerne.org) with the presentation entitled "Reference Networks of Expert Clinics: the experience of the Dyscerne Network". The three main aims and the 3-level 'structure' of the DYSCERNE network, i.e. the 6 main partners, a total of 26 experts drawn from 20 centres specialized in dysmorphology, and a total of 61 centres from virtually every EU country and 7 from non-EU countries (including Turkey) were presented. An overview of how a particular case will move around the Dysmorphology Diagnostic System (DDS) was shown in detail, step by step. The future for DYSCERNE, including key objectives for 2010 and sustainability afterwards was the last part of the talk. Clinical geneticists, who were among the audience, were particularly interested in the system. A heated discussion after all presentations was dedicated to how Turkey could benefit from the experience in order to move forward in policy shaping for rare diseases and orphan drugs.

**Krystyna Chrzanowska, July 2009**