

**Rare Diseases Alliances, Federations and Associations -
as well as Academics -
co-signing the EURORDIS Proposal for
the Practical Implementation of Policy Principles
to Improve Access to Orphan Drugs in the EU**

1. Myeloma Euronet
2. Dr. Eric ABADIE, Direction Générale AFSSAPS (France), Chair of EMEA CHMP (Committee for Medicinal Products for Human Use)
3. Centrum Menselijke Erfelijkheid / Center Human Genetics (Belgium)
4. Cystic Fibrosis Europe (Belgium and Germany)
5. Yolande Avontroodt, Mayor - Chair of the Committee for Science and Technology of the Belgian Federal Parliament
6. Debra International - Dystrophic Epidermolysis Bullosa Research Association
7. Greek Alliance for Rare Diseases
8. EGAN - The European Genetic Alliances' Network
9. BAPES - The Bulgarian Association for Promotion of Education and Science
10. CORD - Canadian Organization for Rare Disorders
11. HUFERDIS – Rare Diseases Hungary
12. GIG - Genetic Interest Group, UK
13. Rare Disorders Denmark
14. Thalassaemia International Federation
15. RADIORG - BOKS (Belgium)
16. Mukoviszidose Institut (Germany)
17. FEDER - Federación Española de Enfermedades Raras
18. UNIAMO – Federazione Italiana Malattie Rare - Italy
19. Pulmonale hypertonie e.v. – Germany

**Individual Companies
endorsing the EURORDIS Proposal for
the Practical Implementation of Policy Principles
to Improve Access to Orphan Drugs in the EU**

1. CSL Behring
2. Genzyme
3. Helsinn
4. IDM Pharma
5. Jerini AG
6. LFB Biomédicaments
7. Orfagen
8. Orphan Europe
9. PharmaMar S.A.
10. Shire HGT
11. Swedish Orphan International

The key principles contained in EURORDIS document have also been supported by the Industry through a joint EBE (EFPIA) - EuropaBio paper entitled: "**Industry Recommendations and Suggestions for the Practical Implementation of Policy Principles to Improve Access to Orphan Medicinal Products in the EU**".