

Common Goals & Mutual Commitments between National Alliances in Europe & EURORDIS: An agenda between 2014 & 2020

EURORDIS & National Alliances aim to the best of their ability and in accordance with available resources to:

- Consolidate their position as the organisations of reference for rare diseases at national level and as European Networks and be recognised as actors in worldwide processes having impacts on patients and families living with a rare disease in Europe;
- Consolidate their activities to raise public awareness, in particular the Rare Disease Day and the European Year for Rare Diseases;
- Facilitate the development and the effective implementation of a unique EU integrated, comprehensive and long-term strategy to address patients' needs everywhere in Europe, driven by patient advocacy, developed through partnership of all stakeholders, and guided by regulations & directives (laws), recommendations & communications (policies), road maps & programmes & guiding principles & expert recommendations (technical guidance);
- Facilitate the development and engage in the effective implementation of national plans & strategies for rare diseases;
- Consolidate their joint policy recommendations and activities in drug development, centres of expertise, European reference networks, biobanks & registries, good clinical practices for diagnosis & care, specialised social services & integration of rare diseases within national social policies, patients' advocates empowerment;
- Strive for and maintain supportive capacity building relationships with their members and empowerment of volunteers; have the objective to become sustainable in terms of human, financial, organisational resources and governance.

The Implementation Plan for the fulfilment of these Common Goals & Mutual Commitments is detailed in the Annex. This Annex is non-binding and comprises the Road Map for the National Alliances and the Council of National Alliances. The Annex is open to revisions and adoption by the Council of National Alliances.

The purpose, background rationale & perspective, and process are expanded on in the Letter from EURORDIS addressed to the National Alliances.

The... (name of national alliance)... has decided at its Board of Directors' meeting on (date) to progressively integrate to the best of their ability and in accordance with available resources these common goals into its strategy & work plans and to commit to all other National Alliances involved in the European Network of National Alliances for Rare Diseases and to EURORDIS to carry out these common activities to the best of its possibilities.

EURORDIS has decided at its Board of Directors' meeting on 23 November to integrate to the best of its ability and in accordance with available resources these common goals into its strategy & work plans and to commit to all National Alliances involved in the European Network of National Alliances for Rare Diseases to carry out these common activities.