

Common Goals & Mutual Commitments between National Alliances in Europe & EURORDIS: An agenda between 2024 & 2030

EURORDIS & National Alliances aim **to the best of their ability and in accordance with available resources** to implement the following Common Goals & Mutual Commitments:

- Consolidate their positions as **the organisations of reference for rare diseases in Europe** and be recognised as actors in worldwide processes that impact people living with a rare disease in Europe. To this end, EURORDIS and National Alliances will collaborate to:
 - Strengthen the European Network of **National Alliances for Rare Diseases** based on the Internal Rules of the Council of National Alliances, and a commitment to the activities of the Council of National Alliances, in sharing information, experience and common activities.
 - Consolidate the **common identity** of EURORDIS and National Alliances as being part of the same network by sharing a common name or subtitle made up of “**Rare Diseases Europe**” (for EURORDIS) or “**Rare Diseases Country**” (for National Alliances).
 - Consolidate the **Membership** of National Alliances in order to cover the majority of all existing rare disease patient groups, including rare cancers and diseases with very low prevalence, at national level so to enhance their representation and inclusiveness.
 - Collaborate with **Rare Diseases International**, to increase visibility and influence in international instances such as WHO, UN and OECD and to move the rare disease agenda forward in line with the United Nations Agenda 2030.
- **Raise public awareness of rare diseases** by working together:
 - **Organise the annual international Rare Disease Day** to raise public awareness and empower the voice of the rare disease community, as the campaign’s official partners and coordinators.
- **Promote and facilitate a new European policy framework** to achieve measurable goals prolonging and improving the lives of people living with a rare disease and promoting their inclusion in society. EURORDIS and National Alliances will:
 - **Focus on priority areas**, such as earlier, faster and more accurate diagnosis; high quality national and European healthcare pathways, including cross border healthcare; integrated medical and social care with a holistic life-long approach and inclusion in society; innovative and patient-led research and knowledge development; optimised data and health digital technologies; development and availability, accessibility and affordability of treatments.
 - Engage in **the Rare Barometer** initiative by providing input to the development of surveys, disseminating surveys to members and beyond on the national level, disseminating results and using them to feed advocacy positions.
 - Contribute to EURORDIS’ **European Conference on Rare Diseases & Orphan Products** in terms of outreach and promotion. Contribute to **NA’s national or cross-national conferences** in terms of planning, programme development, target audiences, official support, mutual promotion.
 - Achieve a “**leave no one behind**” strategy inclusive of genetic and non-genetic rare diseases, rare cancers, rare infections and health hazards and all rare disease prevalence and incidence levels

- Facilitate the development and effective implementation of **national plans and strategies for rare diseases**. EURORDIS & National Alliances will **consolidate their joint policy actions** to:
 - Promote the adoption of **National Plans/Strategies** in each EU Member State, renew them based on benchmarking and iterative upgrading as well as get them adopted or under development in all other European Countries with patient-centered approaches around common strategies and technical recommendations and sharing of good practices.
 - Provide information on the Joint Action on **integration of ERNs into National Health Systems** (JARDIN).

- Develop enriched and more supportive capacity building relationships with members and empowerment of volunteers. National Alliances & EURORDIS should:
 - Encourage good governance and financial practices.
 - Stimulate and facilitate exchange of **information, good practices & common tools to enhance mutual support and learning from each other**; intensify **capacity building and networking** activities of EURORDIS with National Alliances and between National Alliances across Europe both to enhance respective capacities, increase convergence and collaboration between National (ex: CNA meetings and monthly hot topics calls, EURORDIS Membership Meetings, EURORDIS Open Academy)
 - Provide capacity building of patient advocates (ex: EURORDIS Membership Meeting Workshops, EURORDIS Open Academy, e-learning, webinars and Rare Disease Week)
 - Maintain a high level of **legitimacy and credibility** by maintaining a high level of agreement amongst EURORDIS' & National Alliances members as well as a high level of national & European & International public affairs & advocacy alignment amongst EURORDIS & National Alliances & their members
 - Promote **public recognition of National Alliances** and EURORDIS based on the recognition of their role in the RD field.

For EURORDIS – Rare Diseases Europe,

Avril Daly,
EURORDIS, President

For the National Alliances,