

Declaration of membership in other organisations/networks

EURORDIS and its representatives applying to the HTA Stakeholder Network declare membership to the following organisations/networks.

Member of European Not-for-Profit Organisations & Initiatives:

- EPF: European Patients' Forum (founding member)
- EU4Health Civil Society Alliance (founding member)
- Rare Cancer Europe (founding member)
- WECAN: informal network of leaders of cancer patient umbrella organisations active in Europe
- EDF: European Disability Forum
- Social Platform – European Platform of European Social NGOs
- RareResourceNet - European Network of Resource Centres (Board member)
- EFGCP: European Forum for Good Clinical Practice
- Friends of Europe
- FIPRA – International Policy Advisors
- Rare Disease Platform in Paris (founding member)
- Maladies Rares Info Service (French Helpline for RDs)
- Get Real Institute (founding member)
- ARRIGE - The Association for Responsible Research and Innovation in Genome Editing
- RWE4DECISIONS
- TOGETHER4RD
- TRANSFORM
- GO FAIR RD network

International Institutions, Not-for-Profit Organisations & Initiatives:

- RDI: Rare Diseases International (founding member)
- ORPHANET
- IRDiRC: International Rare Disease Research Consortium (founding member)
- Global Commission to end the diagnostic odyssey for children (founding member)
- UDNI – Undiagnosed Diseases Network International
- NGO Committee for Rare Diseases (United Nations, New York) (founding member)
- NEWDIGS: New Drug Development ParadIGmS
- IAPO: International Alliance of Patients' Organizations
- ICORD: International Conference on Rare Diseases and Orphan Drugs (founding member)
- PFMD - Patient Focused Medicines Development Initiative
- CIOMS - Council for International Organizations of Medical Sciences
- International partnerships (MoUs): NORD (USA), CORD (Canada), JPA (Japan), RVA (Australia), CORD (China), RADOIR (Iran)

Member of European Networks & Projects:

- BBMRI Stakeholders Forum
- HTx - Next Generation Health Technology Assessment
- OpenMedicine



- C4C - Conect4Children
- CORBEL – MIUF
- Decentralised Trial Project
- SolveRD – Solving the Unsolved Rare Diseases
- reCOVID consortium IMI2
- EJP RD – European Joint Programme on RD
- EUCAPA - European Capacity Building for Patients
- MoreEuropa - More Effectively Using Registries to support Patient-centered Regulatory and HTA decision-making
- REMEDI4ALL - The European Platform for Medicines Repurposing
- Screen4Care - Shortening the path to RD diagnosis by using newborn genetic screening and digital technologies
- VACCELERATE - pan-European backbone for the acceleration of phase 2 & 3 COVID-19 vaccine trials.
- FACILITATE - Framework for Clinical Trial Participants' Data Reutilization for a Fully Transparent and Ethical Ecosystem
- ERICA – European Rare Disease Research Coordination and Support Action
- TEHDAS – Towards the European Health Data Space
- LIVES