



Together for Rare Diseases (Together4RD) Policy Asks Launch

A new model for collaboration to address areas of unmet need in rare diseases

Thursday 10 November 2022, 14h00-16h00 CET

European Parliament, Brussels, Room P7C050

Held under the auspices of the Czech EU Presidency

Agenda

Moderator: Tamsin Rose (Friends of Europe)	
14:00	Welcome Tamsin Rose
14:05	Opening remarks: Building a rare disease ecosystem that supports collaboration and exchange MEP Stelios Kypouropoulos (EPP, GR)
14:15	Addressing unmet need for people living with a rare disease: unlocking the potential of collaborations Yann Le Cam, CEO, EURORDIS
14:25	Panel discussion <i>What are the challenges to ERN-industry collaboration, and what are Together4RD's proposed solutions? How can decision-makers build on and support a new framework for collaboration?</i> <ul style="list-style-type: none">▪ Andrzej Rys, Principal Scientific Advisor, DG SANTE, European Commission▪ Pr. Alexis Arzimanoglou, ERN EpiCARE Coordinator, Coordinator of the ERN CG▪ Dimitrios Athanasiou, Board Member, World Duchenne Organization▪ Victoria Hedley, Rare Disease Policy Manager, Newcastle University▪ Vittoria Carraro, Director Government Affairs, EUCOPE

15:20	Perspective from the European Parliament considering the forthcoming legislative revisions (video intervention) MEP Ondrej Knotek (CZ, Renew Europe)
15:30	In discussion with Sheela Upadhyaya: Future ambition for Together4RD Sheela Upadhyaya, Chair of Together4RD Steering Group
15:45	Final reflections: A European Action Plan for Rare Diseases as a driver for collaboration to address unmet need MEP Frederique Ries (BE, Renew Europe)
15:55	Close Tamsin Rose
16:00- onwards	Networking coffee

Together4RD is led by a Steering Group with members including ERN Coordinators, representatives from umbrella patient association EURORDIS, the European Joint Programme on Rare Diseases (EJP RD) and Orphanet. DG SANTE act as observers. The companies Alexion, Takeda, Sanofi, Novo Nordisk, UCB and the trade associations EFPIA & EUCOPE offer financial support to the Secretariat, which is coordinated by FIPRA International to support the multi-stakeholder collaboration.