



Press Release

EURORDIS welcomes role in major new research partnership

9 September 2024, Brussels – EURORDIS-Rare Diseases Europe is proud to announce its participation in the newly launched European Rare Diseases Research Alliance (ERDERA), a major new initiative under the Horizon Europe programme co-funded by the European Commission, European Member States, and beyond.

Officially beginning today, ERDERA is set to revolutionise the field of rare disease research, with the mission of accelerating the development of new diagnostics and treatments for the over 30 million people living with rare diseases across Europe.

ERDERA is uniting an unparalleled coalition of more than 170 public and private stakeholders, including 9 patient organisations, research institutions, industry partners, and governmental bodies. Together, this alliance will be driving forward a comprehensive research ecosystem, encompassing everything from funding and education to the translation of research into clinical applications.

As an active partner in ERDERA, EURORDIS will lead efforts in advancing patient education, delivering comprehensive training, and strengthening patient engagement and involvement.

Beyond these areas, EURORDIS is actively contributing to nine of ERDERA's 25 work packages. This includes representing the patient voice and playing a key role in areas such as clinical outcome assessments, engaging underrepresented countries, and collaborating on the public-private accelerator and Advanced Therapy Medicinal Products.

Speaking on the launch of ERDERA, **Roseline Favresse**, Director of Research Policy & Initiatives at EURORDIS, stated:

“We are delighted to welcome the launch of ERDERA, an ambitious partnership with the potential to transform the landscape of rare disease research and establish Europe as a global leader in this vital field. With fewer than 6% of rare diseases having a dedicated treatment and significant gaps in diagnostics, ERDERA presents an unparalleled opportunity to address under-researched areas and propel scientific advancements that will make a lasting difference in the lives of those affected by rare diseases.

“Crucially, ERDERA will set a new standard by deeply embedding patients and their organisations in every step of the research process, including the setting of priorities. This patient-driven approach is key to ensuring that research truly addresses the needs of our community.

“At EURORDIS, we are proud to be leading ERDERA’s efforts in patient involvement, education, and training, fostering a research ecosystem that directly addresses the real-world challenges faced by individuals living with rare diseases.

“ERDERA is also about forging a united front across Europe, aligning national and European strategies, and ensuring that no country or community is left behind. We therefore call on all stakeholders – researchers, policymakers, healthcare professionals, and patient advocates – to join us in the partnership’s ambitious and vital endeavour.”

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting people, families, and rare disease groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies, and services.

Contact

Julien Poulain

Communications Manager

EURORDIS-Rare Diseases Europe

Julien.poulain@eurordis.org

+33 6 42 98 14 32