



Media statement

EURORDIS welcomes effort to integrate ERNs into National Healthcare Systems

6 March 2024, Brussels – On the 6-8 March, there will be the [kick-off](#) meeting in Brussels for the Joint Action on Integration of European Reference Networks (ERNs) into National Healthcare Systems (JARDIN).

Launched in response to the challenges faced by individuals living with a rare and complex condition in Europe, JARDIN is a three-year endeavour aiming to seamlessly connect EU and the Norwegian health systems and the ERNs.

The ERNs serve as a vital infrastructure, connecting healthcare providers, specialists, researchers, and patient representatives from across Europe to share knowledge and collaborate on the treatment and diagnosis of rare and complex diseases. However, it is essential for the ERNs' and national health systems' services and infrastructures to all be better integrated. This integration will allow each health system to benefit from the knowledge and services provided by ERNs, thereby enhancing or developing their abilities to provide better care for individuals with rare and complex conditions.

At the same time, integration is one of the cornerstones for the sustainability of the ERNs. The Networks' *raison d'être* is to improve the health outcomes of all people living with a rare or complex condition, and they can only deliver on this ambition if they are well connected to the local health systems in charge of planning and organising the delivery of healthcare services.

The [recommendations on ERNs integration into national health systems](#) put forth in 2018 by EURORDIS and the rare disease patient community, as well as the recommendations of the [Rare2030 Foresight Study](#) published in 2021, have served to lay the groundwork for action in this critical area. This Joint Action greatly builds on these recommendations, addressing the relevant areas identified years ago.

Led by Professor Till Voigtländer from the Medical University of Vienna, the activities foreseen in this Joint Action will assist health authorities in creating their national integration roadmaps. They will offer concrete recommendations on topics such as patient pathways, national reference networks, processes for undiagnosed patients, quality enhancement for centres of expertise, referral mechanisms, and health data interoperability.

JARDIN will also include Ukraine as an associate partner, allowing for the exchange of knowledge and expertise between Ukrainian patients and clinicians and their EU counterparts. Additionally, the project will also deliver an extension to the Ukrainian Rare Diseases Hub, which is helping people who live with a rare disease to continue accessing healthcare services amidst the disruptions resulting from the war.

On the launch of JARDIN, **Ines Hernando, ERN & Health Director at EURORDIS**, said:

“Our hope is that in the next three years, the Joint Action that kicks off today will take us to a more integrated European Health Union for rare and complex conditions, where national and cross-border healthcare pathways and infrastructures are fully integrated. The launch of JARDIN represents a major milestone in improving the care of rare diseases within Europe and making sure that individuals living with rare diseases receive the highest quality of care, regardless of their geographic location.

“We feel encouraged by the fact that JARDIN has been comprehensively designed, incorporating action in all priority areas to progress towards a European Health Union for rare and complex diseases.

“However, the real measure of JARDIN’s success will be in how well it serves to achieve a fully integrated European healthcare system for rare and complex conditions. Achieving this will require robust leadership from national and regional health authorities, who must develop a clear vision and roadmap to materialise the Networks’ integration within their health system and guide multistakeholder action.

“Within the next three years, we anticipate JARDIN to deliver significant achievements and successes. As we thank everyone who has been part of this initiative, we also reiterate EURORDIS’ steadfast commitment to facilitating this Joint Action and leading the active participation of the rare disease patient community.”

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.

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