



Communiqué

# Yann Le Cam announces departure as Chief Executive Officer of EURORDIS- Rare Diseases Europe

13 September 2023, Paris – Yann Le Cam, who has served as Chief Executive Officer of EURORDIS – Rare Diseases Europe for the past 25 years, has announced his intention to step down from the role. This deliberate choice comes at an opportune moment for EURORDIS, underpinned by strategic considerations and careful planning to ensure seamless leadership continuity.

Le Cam reflected fondly on his tenure, noting EURORDIS' remarkable growth from humble beginnings into a robust organisation with over one thousand member organisations.

*"I've had the privilege of steering the transformation of EURORDIS from a small alliance into a thriving community that has given a voice to people with rare diseases in Europe and created positive change in their lives."*

While bittersweet, Le Cam emphasised that this transition has been prepared for a long time and is happening at the right moment for the organisation to deliver its strategy for 2030.

*"Thanks to Yann's pioneering leadership, EURORDIS is well poised to navigate this period of change" said EURORDIS Board President Avril Daly. "On behalf of the Board, I want to thank Yann for his forward-thinking leadership and unwavering commitment since EURORDIS establishment in 1997. The entire EURORDIS family is excited to see what the next chapter holds."*

To ensure continuity, EURORDIS' Board of Directors have launched a search for Yann's successor, and are seeking a leader who shares the organisation's vision and commitment to improving the lives of the 30 million people with rare diseases across Europe.

Yann will remain CEO until March 2024 and will have an advisory role during the transition period. Beyond his role as CEO, he will continue serving as a EURORDIS representative in international policy and advocacy initiatives. Separately, in his personal capacity, Yann will sustain commitments to initiatives and organisations such as Rare Diseases International, the NGO Committee for Rare Diseases, the Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease and WHO Europe.

*"This is not an ending, but a passing of the torch to a new Chief Executive who will take EURORDIS to even greater heights," concluded Yann.*

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## Contact

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## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1000 rare disease patient 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 patients, families and patient 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 patient services.

## About rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.