



Press release

Award to EURORDIS-Rare Diseases Europe for driving a European Action Plan on rare diseases

16 March 2023, Santiago de Compostela - EURORDIS-Rare Diseases Europe's efforts in driving European Action in rare diseases has today been recognised in an award from FEDER, the Spanish National Alliance for Rare Diseases. The award was presented to Yann Le Cam, Chief Executive Officer at EURORDIS, jointly by HM the Queen of Spain and the Minister of Health, Carolina Darias at a Rare Disease Day event in Santiago de Compostela.

The award honours EURORDIS' leadership in the Rare 2030 Foresight Study, which involved a panel of 250 experts and over 4000 patients, and its subsequent call for a European Action Plan on Rare Diseases. The study published its recommendations in 2021 after two years of participatory research to define how future policies could deliver for the 30 million people living with a rare disease in Europe.

Attending the official Rare Disease Day event in Santiago de Compostela, Yann commented on receiving the award, "This is not just an award for EURORDIS but for our tireless community of 30 million people living with a rare disease in Europe and their families, healthcare professionals, academics and everyone who works in the field, who have jointly contributed to this effort through the Rare 2030 Foresight Study and beyond.

We have seen the need for a European Action Plan on Rare Diseases recognised by over 20 EU Member States who endorsed the Call to Action under the Czech Presidency of the EU Council. With Spain receiving the baton for the next Presidency later this year, the timing of this award is extremely significant, and we hope they will continue to show leadership in driving the EU agenda on rare diseases."

The President of FEDER, Juan Carrión Tudela, added, "The need to work at the European level in the area of rare diseases to share knowledge, data and expertise is undeniable. That is why we are incredibly proud to recognise EURORDIS' efforts in leading the Rare 2030 Foresight Study. Spain were active partners in this study, holding a conference to bring together experts to recognise the national perspective, and we are incredibly impressed with the clarity of direction in the output.

We strongly believe that a European Action Plan on Rare Diseases is needed to ensure a better future for all people living with a rare disease in Spain and Europe, and hope we can count on Spain to lead the way on this during their Presidency of the EU Council."

Rare 2030 set out a clear direction of travel, highlighting the need for a long-awaited European Action Plan on Rare Diseases. It has been 14 years since the last European strategy on rare diseases and the 30 million affected Europeans need to see progress in the policies in place at this level, introducing measurable goals for the whole Union to work towards.

EURORDIS' efforts have gathered momentum and recognition from European institutions, mobilising the European Parliament, European Union Member States and the wider community to act. With the support of the patient community, healthcare professionals, academics, and policymakers, EURORDIS is committed to driving change and improving the lives of people living with rare diseases across Europe.

The event "Make time work in our favour" (Haz que el tiempo vaya a nuestro favor) is taking place in Santiago de Compostela to mark Rare Disease Day celebrations in Spain. Her Majesty Queen Letizia of Spain presides over the event, also attended by Carolina Darias, Health Minister in Spain and officials from the region of Galicia. The objective of the event is to drive an international movement to address the difficulties in equal access to diagnosis and treatments for people living with a rare disease.

About Rare 2030 Foresight Study

The Rare 2030 Foresight Study, initiated by the European Parliament and funded by the European Commission, published its recommendations a year ago. Over two years, 250 experts, thousands of patients and a group of Europe's Young Citizens were mobilised through consultations, interviews, surveys and conferences to agree on what the next decade of rare disease policies should look like. This resulted in eight recommendations to meet the unmet needs of people living with a rare disease by 2030, including for a new European policy framework.

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 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 FEDER, Federación española de enfermedades raras

The Spanish rare disease national alliance, Federación Española de Enfermedades Raras (FEDER) has two decades of experience giving the voice to more than three million people who live with a rare disease in Spain. It is the union of more than 400 entities and associations, representing more than 1400 rare diseases and over 103,000 people. Present across all regions of Spain, FEDER has broadened its impact to act beyond borders, working together with the European and Latin American alliances (EURORDIS and ALIBER, respectively), and Rare Diseases International. Looking to promote the rights of those who live with a rare disease and those in search of a diagnosis by generating strategies which

contribute towards an improved quality of life, FEDER's vision is to be a cohesive community with effective participation across all the areas that are affected by rare diseases through the values of courage, joint responsibility, union, confidence and proximity.

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