

## Press release

## EURORDIS welcomes Spanish EU Presidency's commitment to addressing rare diseases

15 June, Brussels – EURORDIS-Rare Diseases Europe has welcomed Spain's announcement of its policy priorities for the upcoming Spanish Presidency of the EU Council, which begins in July.

The overarching priorities of the upcoming Presidency were outlined today by Spanish Prime Minister Pedro Sánchez.

It has also <u>been confirmed</u> by the Spanish government that "the approach to rare diseases and mental health problems" will be "priorities on the health agenda of the Spanish Presidency".

Responding to the Spanish EU Presidency's health priorities and the inclusion of rare diseases, **Yann Le Cam, Chief Executive Officer of EURORDIS**, said:

"The Spanish EU Presidency's explicit prioritisation of the approach to rare diseases will bring much encouragement to our community. Spain's commendable leadership in this area will build further political momentum towards a comprehensive EU strategy that addresses the many unmet needs of those living with rare diseases. In particular, we hope that the Spanish Presidency may bring the EU closer to delivering a European Action Plan for Rare Diseases.

"People with rare diseases often face challenges in accessing new and effective treatments, and the Spanish EU Presidency's efforts to foster greater pharmaceutical innovation and to expand the joint procurement of transformative medicines are incredibly important to our community. With the European Commission's recent landmark proposals to deliver needed treatments and boost innovation, and given that the WHO Europe Novel Medicines Platform is now live, the Spanish EU Presidency will play a pivotal role over the coming months in refining and improving these proposals.

"We also welcome the commitment to mental health as a health priority, as people living with a rare disease are three times more likely than the general population to experience depression or sadness, and they deal with very unique challenges to their psychological wellbeing. Last month at our Membership Meeting, we launched the EURORDIS Mental Wellbeing Partnership Network to connect our members and experts, and to actively contribute to the European Commission's recently launched strategy on mental health.

"The Spanish EU Presidency is also correct to place an emphasis on consolidating the EU's Social Pillar and advancing legislative initiatives that affect vulnerable populations, including people living with a rare disease. By focusing on children, women, and people with disabilities, the Spanish EU Presidency can contribute to creating an inclusive and equitable society for all, that leaves no one behind.

"Given their complexity and their highly dispersed patient populations, rare diseases clearly present an area where Europe coming together demonstrates value to citizens. Just as the challenges presented by rare diseases span national borders, so do the solutions to these challenges.





"As Spain embarks on its EU Presidency, we look forward to supporting and informing leadership in addressing the challenges faced by people with rare diseases through meaningful action."

Over the course of the Spain's EU Presidency, EURORDIS looks forward to working closely with the Spanish community of rare disease advocates, including the <u>Federación Española de Enfermedades Raras</u> (FEDER).

## **About EURORDIS-Rare Diseases Europe**

<u>EURORDIS-Rare Diseases Europe</u> 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



