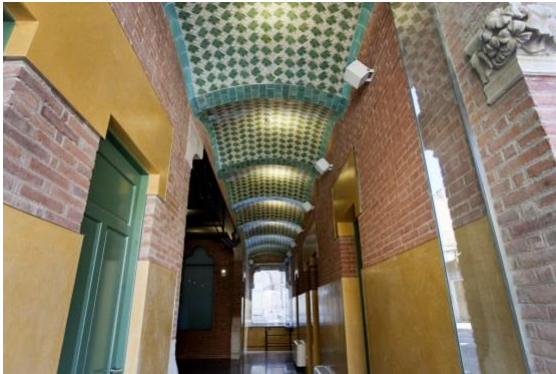


PRESS RELEASE

## New Rare Disease Platform launches in Barcelona

**31 March 2016, Barcelona** - [EURORDIS](#), the European Organisation for Rare Diseases, today launches a new Rare Disease Platform in Barcelona.



The Rare Disease Platform will be housed at the historic Santa Apollònia Pavilion of the [Sant Pau Art Nouveau](#) site, Barcelona and brings together the activities of local, national, European and international rare disease patient groups.

The Platform will host new offices for EURORDIS (including its RareConnect initiative and members of team that support EURORDIS activities at the European Medicines Agency), the [Plataforma](#)

[Malalties Minoritàries](#) and other rare disease organisations in the future.

Speakers at an inauguration event taking place today include:

- Encarna Guillén, Regional Minister of Health, Region of Murcia
- Albert Salazar, Director, Hospital Sant Pau de Barcelona
- Alba Ancochea, Director, [FEDER](#), the Spanish national alliance for rare diseases and EURORDIS member organisation
- Anders Olauson, Chairman, Ågrenska Resource Centre, Sweden
- Terkel Andersen, EURORDIS President, and Yann Le Cam, EURORDIS Chief Executive Officer

The inauguration evening will include discussions on the situation for rare disease patients locally in the region of Catalonia and nationally in Spain, on rare disease initiatives at a European and international level, as well as testimonials from several people whose family members are living with a rare disease.

The UNESCO world heritage Sant Pau Art Nouveau site is home to the Knowledge Centre, which gathers leading institutions in the fields of sustainability, health and education such as the World Health Organisation and the United Nations.

This Rare Disease Platform is made possible thanks to the [Fundació Privada Sant Pau](#).

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## **Rare Diseases**

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering 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.

## **EURORDIS**

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing over 700 rare disease patient organisations in 63 countries. EURORDIS represents the voice of an estimated 30 million people living with a rare disease in Europe. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information visit: [www.eurordis.org](http://www.eurordis.org)

## **RareConnect**

[RareConnect](#) is a platform where rare disease patients, families and patient organisations can develop online communities and conversations across continents and languages. RareConnect partners with rare disease patient groups to offer global online communities allowing people to connect around issues which affect them while living with a rare disease. RareConnect is an initiative of EURORDIS. Follow [@RareConnect](#) or see the [RareConnect facebook page](#). For more information visit: [www.rareconnect.org](http://www.rareconnect.org).

## **Press contacts**

Iolanda Arbiol  
Institutional Relations & Project Manager  
Plataforma Malalties Minoritàries  
[Iolanda.Arbiol@uab.cat](mailto:Iolanda.Arbiol@uab.cat)  
Telf: +34 934337633 /+34 609185470

Eva Bearryman  
Junior Communications Manager  
EURORDIS  
[eva.bearryman@eurordis.org](mailto:eva.bearryman@eurordis.org)  
+33 1 56 53 52 61