



RAISING YOUTH VOICES 2026

Agenda

4 FEBRUARY | BARCELONA



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National Organization
for Rare Disorders



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RAISING YOUTH VOICES



Raising Youth Voices is a new initiative designed to ensure that young people around the world are included in conversations that will define the next generation of policy, research, care, and community support for rare diseases. The event will bring together youth representatives from different world regions to exchange experiences, build networks, and contribute to discussions on youth engagement, patient advocacy, and inclusive health policymaking.

The Roundtable will take place at **3:00 PM (CET)** on **Wednesday, 4 February 2026**, at the **Recinte Modernista de Sant Pau, Barcelona, Spain**.

3:00pm - 4:00pm Panel Discussion
4:00pm - 5:30pm Networking Coffee

The panel discussion will also be broadcast on the Rare Disease Day YouTube channel for those unable to be there in-person.

With thanks to our partner organisations:



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Realised with the support of Fondation Ipsen,
under the aegis of Fondation de France.



THE PANEL



Moderated by Rhiannon Walls, Global Rare Disease Day Lead at EURORDIS-Rare Diseases Europe.



Liam McCarthy is 21 and from Atlanta, USA, living with classic congenital adrenal hyperplasia. He amplifies youth voices through innovative social media campaigns and patient advocacy work.



Maksym Biskubskyi is 27 from Kyiv, Ukraine, living with recessive dystrophic epidermolysis bullosa. He works to advance inclusion of people with rare diseases in sport and public life.



Yu Su is 25 from Chongqing, China, living with spinal muscular atrophy. She leads youth-driven inclusion projects advancing accessibility in higher education.



Pablo Ramirez Uribe is 30 from Colombia living with APS-1. He develops policy toolkits linking global rare disease frameworks with regional stakeholders.



Vincent Mugwati is 22 from Gweru, Zimbabwe. He leads awareness and policy-focused initiatives engaging young people and future healthcare providers.



Stephanie Taylor is 30 from Australia and a parent advocate whose daughter lives with INAD. She leads awareness and community-building initiatives through The INAD Foundation Australia.

