



SPONSORSHIP PROSPECTUS

Partner with the first pan-European initiative
to harmonise Rett syndrome care.

6-7-8 November 2026 | Hotel ILUNION Atrium, Madrid | Invitation-only



A Rett Syndrome Europe initiative
www.rettsyndrome.eu

An invitation

Rett Syndrome Europe (RSE) invites you to support Rett Forum — the first pan-European expert convening dedicated to advancing the standard of care for Rett syndrome.

About Rett syndrome

Rett syndrome is a rare genetic neurological disorder that affects predominantly girls: approximately 1 in 10,000 live female births. It is caused by mutations in the MECP2 gene and leads to profound and multiple disabilities affecting communication, movement, breathing, and daily function.

People with Rett syndrome are individuals with rich inner lives — they communicate through eye gaze and body language, enjoy social connections, music, and the outdoors.

There is currently no approved disease-specific treatment in Europe, though more than 25 companies globally are actively working on therapies — from gene therapies to pharmacological treatments.

About Rett Syndrome Europe

RSE is a parent-led, not-for-profit organisation founded in 1994, representing more than 30 national Rett syndrome associations across Europe. Every board member is a parent of a person with Rett syndrome.

- More than 30 national member associations
- Families across more than 30 European countries
- Scientific Advisory Board of 13 leading international experts
- rettX, the pan-European patient registry (~500 patients from 30+ countries)

About Rett Forum

Rett Forum brings together around 60 leading clinicians, researchers, young scientists, patient advocates, and national association representatives for focused collaboration.

Objectives

- Draft European guidelines for the standard of care in Rett syndrome
- Establish six thematic working groups with 2-year workplans
- Strengthen representation of underrepresented countries
- Support young scientists and early-career researchers
- Build a sustainable European research and care network with rettX

Working groups

- WG1: Communication and AAC
- WG2: Neurology, breathing, and autonomic function
- WG3: Mobility, scoliosis, and motor function
- WG4: Nutrition, GI, and growth
- WG5: Wellbeing, pain, and daily management
- WG6: Clinical trial readiness in EU

Programme

- Day 1: Arrivals and networking
- Day 2: Plenary sessions + parallel working group sessions
- Day 3: Consolidation, governance, and commitments

Why sponsor Rett Forum?

For your organisation

- Direct engagement with the European Rett syndrome expert community
- Visibility as a supporter of European rare disease collaboration
- Alignment with care standards shaping clinical practice across Europe
- Association with rettX — the pan-European patient registry

For the Rett community

- Directly enables the first European Rett care guidelines process
- Travel grants for young scientists from underrepresented countries
- Working groups continue beyond the event for lasting impact

Sponsorship tiers

Benefit	Platinum	Gold	Silver	Supporter
Contribution	from 15,000 EUR	from 8,000 EUR	from 4,000 EUR	from 1,000 EUR
Logo on programme	Large	Medium	Small	Listed
Logo on webpage	Featured	Standard	Standard	Listed
Opening plenary	Named	Named	As group	--
Named break	Choice	Assigned	--	--
Exhibition table	Dedicated	Shared	--	--
Outcomes report	Full	Full	Summary	Summary
Social media	Dedicated	Shared	Shared	--
Photocall backdrop	Large logo	Medium logo	Small logo	Logo listed
Founding sponsor	Yes	--	--	--

In-kind sponsorship is also welcome — venue, catering, travel grants, AV, or printing.

Independence commitment

RSE is committed to maintaining full independence of the Rett Forum scientific programme:

- The Scientific Advisory Board sets the agenda; sponsors have no veto rights
- Industry may contribute evidence but do not chair working groups
- No exclusive sponsorship — multiple sponsors ensure balance
- All sponsorships are publicly acknowledged and disclosed

This commitment protects both RSE's credibility and the value of your sponsorship — the outcomes carry weight precisely because they are independent.

How to get involved

To discuss sponsorship or explore in-kind contributions, please contact:

Sponsorship Coordinator

Rett Syndrome Europe

Email: forum@rettsyndrome.eu

Web: www.rettsyndrome.eu



Rett Syndrome Europe is a parent-led, not-for-profit organisation founded in 1994.

We walk this path ourselves — and we invite you to walk it with us.