



RETT FORUM

EUROPEAN EDITION 2026

6–8 November 2026
Madrid, Spain

**Science, care and
families, together.**

Programme

Three days of strategic inputs and working group development. Two parallel tracks share plenaries, breaks and joint sessions.

Working groups

Six thematic groups of clinicians, researchers and patient advocates agree scope, priorities and a post-Forum plan.

Patient representatives

RSE General Assembly and dedicated sessions with our industry partners.

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WORKING GROUPS

PATIENT REPRESENTATIVES

Friday 6 November

Arrivals and informal networking

14:00 16:00	Registration, arrivals and informal welcome	
16:00 16:30	Opening welcome and practical orientation RSE leadership and the SAB Chair	
16:30 17:00	Informal networking and introductions	
17:00 18:00	Meet your working group Chairs, topic and first priorities	Open discussion
18:00 19:00	Unstructured networking	
19:30 21:00	Networking dinner	

Saturday 7 November

Strategic inputs and working group development

08:00 09:00	Breakfast	
09:00 09:20	Strategic plenary 1: Forum objectives and output expectations	
09:20 09:45	Strategic plenary 2: Methodology for future guidance and consensus outputs	
09:45 10:30	Plenary 3: Patient involvement in the regulatory process: the role of patient experience data <i>Dr Kieran Breen, Vice-Chair, CAT, European Medicines Agency</i>	
10:30 11:00	Coffee break	
11:00 12:30	Working group session 1 Scope, gaps and priority questions	RSE General Assembly Part 1
12:30 14:00	Lunch	
14:00 15:30	Working group session 2 Priority action areas and evidence needs	RSE General Assembly Part 2
15:30 16:00	Coffee break	
16:00 17:00	Cross-working group exchange Dependencies and shared issues	Industry sessions UCB, Acadia, Anavex
17:00 18:00	Working group session 3 Workstreams and leads	Industry sessions Neurogene, Taysha, Lundbeck, Reverta
18:00 18:30	End-of-day output check	
19:30 21:00	Dinner	

Sunday 8 November

Final outputs, action plans and roadmap

09:00 10:30	Working group session 4 Consolidate scope, priorities and post-Forum plan	Industry round table All industry partners
10:30 11:00	Coffee break	
11:00 12:30	Working group progress review	
12:30 13:30	Lunch	
13:30 14:30	Joint roadmap session European Rett research and care network	
14:30 15:00	Implementation commitments and governance	
15:00 15:30	Closing session	