

CONVERGENCE OF SCIENCE AND HOPE

11-12 October 2025
İstanbul



www.rettsendromu.org
www.rett syndrome.eu



www.metaturizm.com

Dear Supporter,

We are honored and pleased to announce the International Conference on RETT Syndrome, which will be held in Istanbul on October 11-12, 2025, and to invite you, our esteemed colleagues.

Rett Syndrome is a unique postnatal disorder that can be diagnosed in infancy and almost always affects girls. It is very rarely seen in boys. The incidence is estimated between at 1/10,000 to 1/20.000.

Rett syndrome is caused by mutations in a gene called MECP2 on the X chromosome. More than 200 different types of mutations have been identified in the MECP2 gene. Most of these mutations are found in eight different "hot spots".

Rett syndrome causes problems with brain function responsible for cognitive, sensory, emotional, motor and autonomic function. These problems can include one or more of learning, speech, sensory perception, mood, movement, breathing, heart function and even chewing, swallowing and digestion.

In addition to its low incidence, Rett syndrome is often misdiagnosed as Autism, Cerebral Palsy or non-specific developmental delay. For this reason, it is categorized as a rare disorder with low awareness.

Rett syndrome has shown reversibility in lab mice even at the later stages of development which encouraged a huge surge in research into the disorder. Studies in this direction accelerated in 2023 with the launch of the first commercial drug, DayBue (Trofinetide) by Acadia Pharma, with a symptom-reducing effect specific to Rett syndrome and the initiation of the "human trial" phase of genetic studies for treatment by many different companies.

The Rett Syndrome European Congress aims to bring together its members, scientists, clinicians, educators, experts and all other stakeholders to share their current knowledge and experiences with each other.

Let's Shape the Future Together with Science and Hope

The purpose of our conference is not only to share knowledge, but also to instil hope for a brighter future. Each participant's contribution to this journey will be an important step in the fight against Rett syndrome.

CONFERENCE CO- PRESIDENT

Mrs. Becky Jenner – Chairman, Rett Syndrome Europe

Mr. Burak Temiz – Chairman, Turkish Rett Syndrome Families Assistance Solidarity Association

SPONSORS

1- Main Sponsor

Acadia Pharmaceuticals



Acadia is the main conference sponsor for to support families travel and accommodation. Conference attendees will be RETT families, RSE (board) members, HCPs, and industry representatives.

- (1) – [Acadia Pharmaceuticals: Elevate Life](#)
- (2) – [Acadia Pharmaceuticals Inc.: Posts | LinkedIn](#)

2- Printed Material Sponsor

Tysha Gene Therapies



Tysha Gene Therapies has approved a sponsorship to support the International Rett Syndrome Conference for the notepad and pen.

- (1) - www.tayshagtx.com

ASSOCIATIONS ORGANISING THE CONFERENCE

Turkish Rett Syndrome Families Assistance Solidarity Association – www.rettsendromu.org

Rett Syndrome Europe – www.rettysyndrome.eu

CONFERENCE PRESIDENTS

Mrs. Becky Jenner - Chairman, Rett EU

Mr. Burak Temiz - Chairman, Rett TR

ORGANISATION COMMITTEE

Mrs. Becky Jenner (RSE Europe President)

Mr. Burak Temiz (RS Association Turkey President)

Assoc. Prof. Gamze TEMİZ (University of Health Sciences)

Mrs. Badegül Yaşar (RS Association Turkey member of BoD, Treasurer)

SCIENTIFIC AND ADVISORY BOARD

Prof. Dr. Yasemin Alanay– Pediatric Genetics and Teratology – Acibadem University-Istanbul

Assoc. Prof. Dr. Gamze Temiz – Internal Medicine – Health Science University - Istanbul

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Dr. Ayfer Arduç Akçay – Pediatric Neurology – Koc University

Dr. Ebru Ekmekçioglu – Anesthesia and Reanimation - City Hospital of Konya - Konya

Dr. Nazli Busra Acikgoz –Pediatric Genetics - Hacettepe University Ankara

CONFERENCE SECRETARY

Assoc. Prof. Dr. Gamze Temiz – Internal Medicine – Health Science University - Istanbul

ORGANISATION SECRETARY

Mrs. Badegül Yaşar (RS Association Turkey member of BoD, Treasurer)

SCIENTIFIC TOPICS AND PROGRAMME

Saturday 11th October 2025: First Day

08:30 - 09:30 | Registration and Opening Breakfast/Tea-Coffee Presentations

09:30 - 10:00 | Opening Speeches

- Speeches by Rett Syndrome Association of Turkey and RSE representatives.
- Introduction of the main theme of the conference.

10:00 - 11:00 | Session 1: From Genetic Research to Clinical Applications

- Information on genetic treatment studies.
- New scientific discoveries and treatment approaches.

11:00 - 11:15 | Coffee Break

11:15 - 12:15 | Session 2: Neurology and Rett Syndrome

- Neurological effects of Rett syndrome.
- Research on brain functions.

12:15 - 13:30 | Lunch and Networking

13:30 - 14:30 | Session 3: Speech and Language Therapy

- Communication development methods for individuals with Rett syndrome.
- Alternative and supportive communication tools.

14:30 - 15:30 | Session 4: Physiotherapy and Movement Development

- Supporting motor skills.
- The importance of physiotherapy and application examples.

15:30 - 15:45 | Coffee Break

15:45 - 16:45 | Session 5: Respiratory System in Rett Syndrome

- Respiratory system problems

15:45 - 16:45 | Workshop: Drug Applications

- Effects of drugs used in Rett syndrome and treatment methods.
- Practical examples from experts.

16:45 - 17:15 | Summary of the Day and Discussion

SCIENTIFIC TOPICS AND PROGRAMME

Sunday 12th October 2025: Second Day

09:00 - 09:30 | Breakfast and Social Activities

09:30 - 10:30 | Session 6: Nutrition and Metabolism

- Nutritional regimen for individuals with Rett syndrome.
- Methods supporting metabolism.
- Understanding the gut microbiota and microbiome changes in Rett syndrome

10:30 - 11:30 | Session 7: Gynaecology and Gynaecological Concerns

Puberty and management in individuals with Rett syndrome.

11:30 - 11:45 | Coffee Break

11:45 - 12:45 | Session 8: Global Collaborations, Awareness, Registration of Individuals with Rett Syndrome

- The importance of establishing a European Rett syndrome registry
- Rett syndrome awareness studies in the world.
- The importance of international collaborations.

12:45 - 14:00 | Lunch and Networking

14:00 - 15:00 | Workshop: Improving the Quality of Life of Individuals with Rett Syndrome

- Difficulties encountered in daily life and solutions.
- Support programmes for families.

15:00 - 15:45 | Closing Session: The Future of Science and Hope

- General evaluation of the conference.
- Open forum and Q&A with participants.

16:00 - 17:00 | Certificate Distribution and Closing Cocktail

GENERAL INFORMATION OF THE CONFERENCE

Conference Date:

11-12 October 2025

Conference Centre:

Acibadem University Faculty of Medicine Campus Kartal, 34880 İstanbul

Transport:

The Conference Centre is 55 km from İstanbul Airport (IST) and 12 km from Sabiha Gökçen Airport (SAW). Airport-Hotel-Airport transfers will be made in parallel with flight times. Transfers are paid and arrival and departure times must be notified at least 7 days in advance.

Hotel - Conference Hall - Hotel transportation will be provided free of charge by the Conference Secretary.

For detailed information, please contact Meta Tourism.

Lunch:

Lunch will be served as a "Selectable Set Menu" at the Acibadem University Campus Cafeteria. Set menus will include a starter, appetizer/salad, main course, dessert, and a beverage. Main courses can be selected from chicken, meat, or vegetable dishes. Alcohol is not served at lunch.

Symposium Language:

Conference language English (Simultaneous translation will be available)

Cancellation Conditions:

Cancellations of participation and accommodation must be notified in writing until September 01, 2025. Cancellations after September 01, 2025 will not be refunded.

REGISTRATION & ACCOMMODATION

Conference Registration	Before September 01, 2025	After September 01, 2025
Participant from industry	200 Euro	250 Euro
Participant scientist/experts	150 Euro	175 Euro
Representatives of Rett Syndrome Organizations	100 Euro	100 Euro
Rett families	Free of charge	Free of charge

Registration fee includes participation in scientific activities, participation certificate, Conference bag, notepad, pen, USB, lunches and coffee breaks, excluding Gala Dinner and 20% VAT.

Accommodation		
Hotel	Single	Double
Selectum City Atasehir Hotel (5*)	225 Euro	250 Euro

Accommodation fees; 2 nights 10 October 2025 check-in (C/In) - 12 October 2025 check-out (C/Out)) Bed + breakfast is included, excluding 10% VAT + 2% accommodation tax.

Conference Registration Accommodation Bank Account No	
Account Name	META TURİZM YAT.SAN.ve TİC.LTD.ŞTİ
Bank Name	YAPI KREDİ BANKASI
Branch Name and Branch Code	ACIBADEM - 839
TL Account No	TR06 0006 7010 0000 0025 5928 58
EURO Account No	TR16 0006 7010 0000 0028 3744 44
SWIFT	YAPITRISXXX



Conference Organization: META TURİZM

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