

# PROGRAMME

**7 & 8**  
OCTOBER  
**2023**

WORLD TRADE CENTER  
**MARSEILLE**

Organized by  
the French Association  
of Rett Syndrome



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## SATURDAY 07 OCTOBER

PLÉNIÈRE 1

### 09:00-10:40 POLITICAL INVOLVEMENT

- 09:00-09:10 • **Opening speech.** Mr. Julien FIESCHI, Chairman of the AFSR
- 09:10-09:30 • **TBC.** Ms. Fadila KHATTABI Fadila KHATTABI, Minister for Solidarity and the Family
- 09:30-09:40 • **Political involvement.**
- 09:40-09:50 • **Political involvement.**
- 10:10-10:40 • **Health data applied to rare diseases: review of the national plan for rare diseases 3 and prospects for the national plan for rare diseases 4 in 2024.**  
Ms. Anne-Sophie LAPOINTE, Project manager for the rare diseases mission

### 10:40 COFFEE BREAK

### 11:00-12:45 POLITICAL INVOLVEMENT

- 11:00 - 11:30 • **PNDS or Rett center.** Mrs. Nadia BAHY-BUISSON
- 11:30 - 12:15 • **Transition to majority.** Mrs. Perrine CHARLES
- 12:15 - 12:45 • **Rett Syndrome Europe (RSE).** Mrs. Rebecca JENNER, President, Rett Syndrome Europe

### 12:45-13:45 LUNCH COCKTAIL

### 13:45-16:00 NATURAL HISTORY & COMORBIDITIES

- 13:45-14:30 • **Gene discovery to clinical trials : How clinical and basic research have intersected to develop and test new therapies for Rett syndrome.**  
Mr. Jeffrey NEUL, Director, Kennedy Center at Vanderbilt
- 14:30-15:15 • **Natural History of RTT and discovery of Mecp2.**
- 15:15-16:00 • **Description of the RTT pathology and its evolution over time.**

### 16:00 COFFEE BREAK

### 16:15-19:45 NATURAL HISTORY & COMORBIDITIES

- 16:15 - 16:45 • **Epilepsy and Rett.**
- 16:45 - 17:15 • **Dysautonomia and Erratic Breathing in Rett Syndrome.**  
Pr. Jan-Marino RAMIREZ, Director
- 17:15 - 18:15 • **Disturbances in breathing and sleep: a state of the art.** Pr. Karen SPRUYT, Researcher
- 18:15 - 19:00 • **Medical and physical follow-up of adults with Rett syndrome; experiences from a national Rett center.** Mrs. Anne-Marie BISGAARD, Consultant, PhD
- 19:00 - 19:45 • **Genetics of Rett syndrome made simple (for parents and families).**  
Mr Laurent Villard, Head of Human Neurogenetics Laboratory



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**SUNDAY 08 OCTOBER**

**PLÉNIÈRE 1**

**09:00-10:30 INNOVATIVE THERAPIES IN RTT**

- 09:00 - 09:30 • **Neural precursor cell therapy rescues pathological signs of Rett syndrome.**  
Pr. Nicoletta LANDSBERGER, Full Professor of Molecular Biology
- 09:30 - 10:00 • **Pharmacology.**  
Mr Jean-Christophe ROUX, Chairman of the Medical and Scientific Council
- 10:00 - 10:30 • **Genetic and epigenetic determinants of reactivation of MeCP2 and the inactive X chromosome in neural stem cells.** Mr. Joost GRIBNAU, Head of Department of Developmental Biology

**10:30 COFFEE BREAK**

**11:00-12:30 MEDICAL AND PARAMEDICAL SUPPORT 1**

- 11:00-11:45 **Rett Communication Guidelines.** Mrs Gillian TOWNEND, (1) Lecturer and researcher at the University of Reading, UK (2) Head of Research at Rett UK
- 11:45-12:30 **State of clinical research on multiple disabilities in Europe.** Mr. Stéphane JULLIEN

**11:00-12:30 MEDICAL AND PARAMEDICAL SUPPORT 2**

**PLÉNIÈRE 2**

- 11:00-11:45 **Physical therapy.** Mr. Meir LOTAN, Physiotherapist
- 11:45-12:30 **Motricity.** Mr. Meir LOTAN, Physiotherapist

**12:30 LUNCH COCKTAIL**

**13:30-15:00 MEDICAL AND PARAMEDICAL SUPPORT 1**

- **AAC and literacy in Rett syndrome.** Mrs. Albane PLATEAU
- **Advanced technologies for cognitive and motor telerehabilitation in Rett Syndrome: Amelie and Tele-Airett.** Mrs. Martina SEMINO, Mrs. Michela PERINA

**13:30-15:00 MEDICAL AND PARAMEDICAL SUPPORT 2**

**PLÉNIÈRE 2**

- **Nutrition, orality and Rett syndrome.** Mrs. Laure SOULEZ-LARIVIÈRE, Dietician-nutritionist and speech therapist
- **Nutrition, morality and Rett syndrome.** Mrs. Laure SOULEZ-LARIVIÈRE, Dietician-nutritionist and speech therapist