

**SAVE THE DATE**

**6.7.8**  
**OCTOBER**  
**2023**

**7<sup>th</sup>** European  
Rett  
Syndrome  
Conference

WORLD TRADE CENTER  
**MARSEILLE**

Organized by  
the French Association  
of Rett Syndrome

**AFSR**

Association Française du Syndrome de Rett  
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7 & 8  
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MARSEILLE









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Saturday 07 October

09:20	<div>09:20 - 10:20</div> <div>COLLECTIVE COMMITMENT TO RARE DISEASES</div> <div>Welcome address. <b>Julien FIESCHI</b> (France, France)</div> <div>Opening speech. <b>Fadila KHATTABI</b> (France)</div> <div>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. <b>Anne-Sophie LAPOINTE</b> (France)</div>	Plénière 1
10:20	COFFEE BREAK	
10:45	<div>10:45 - 12:15</div> <div>COLLECTIVE COMMITMENT TO RARE DISEASES</div> <div>PND5 or Rett center. <b>Nadia BAHI-BUISSON</b> (France)</div> <div>Rett Syndrome Europe (RSE). <b>Rebecca JENNER</b> (Royaume-Uni)</div> <div>Sponsored by ACADIA: Trofinetide for the Treatment of Rett Syndrome. <b>Kathie BISHOP</b> (SAN DIEGO, USA)</div> <div># - CO1 NEAT1 dysregulation in Rett syndrome: unveiling pathological mechanisms and therapeutic potential. <b>Edilene SIQUEIRA</b> (Barcelona, Spain), <b>Tara SRINIVAS</b>, <b>Ariadna TARRASON</b>, <b>Deepthi RAMESH-KUMAR</b>, <b>Marta SOLER</b>, <b>Sonia GUIL</b></div> <div># - CO2 Being a parent of an individual with Rett syndrome in a lifelong perspective: A qualitative study of the parents' experiences. <b>Jane LUNDING LARSEN</b> (Copenhagen, Denmark), <b>Michelle STAHLHUT</b>, <b>Anne-Marie BISGAARD</b>, <b>Helena HANSSON</b></div>	Plénière 1
12:00	<div>12:00 - 13:30</div> <div>LUNCH COCKTAIL</div>	
13:30	<div>13:30 - 15:30</div> <div>NATURAL HISTORY &amp; COMORBIDITIES</div> <div>Gene discovery to clinical trials : How clinical and basic research have intersected to develop and test new therapies for Rett syndrome. <b>Jeffrey NEUL</b> (Etats-Unis)</div> <div>Natural History of RTT and discovery of Mecp2. <b>Nadia BAHI-BUISSON</b> (France)</div> <div>Epilepsy and Rett. <b>Mathieu MILH</b> (Marseille)</div>	Plénière 1
15:30	COFFEE BREAK	
16:00	<div>16:00 - 18:15</div> <div>NATURAL HISTORY &amp; COMORBIDITIES</div> <div>Dysautonomia and Erratic Breathing in Rett Syndrome. <b>Jan-Marino RAMIREZ</b> (Etats-Unis)</div> <div>Disturbances in breathing and sleep: a state of the art. <b>Karen SPRUYT</b> (France)</div> <div>Medical and physical follow-up of adults with Rett syndrome; Experiences from a national Rett center. <b>Anne-Marie BISGAARD</b> (Danemark)</div>	Plénière 1
19:00	<div>19:00 - 20:00</div> <div>COCKTAIL</div>	



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"Sunday 08 October"		
Sunday 08 October		
<div>09:00</div> <div>10:30</div> <div>11:00</div> <div>12:30</div> <div>13:30</div>	09:00 - 10:30 <b>INNOVATIVE THERAPIES FOR RETT SYNDROME</b>	
	Neural precursor cell therapy rescues pathological signs of Rett syndrome. <b>Nicoletta LANDSBERGER</b> (Italie) Pharmacology. <b>Jean-Christophe ROUX</b> (France) Genetic and epigenetic determinants of reactivation of Mecp2 and the inactive X chromosome in neural stem cells. <b>Joost GRIBNEAU</b> (Pays-Bas)	Plénière 1
	COFFEE BREAK	
	11:00 - 12:30 <b>MEDICAL AND PARAMEDICAL SUPPORT 1</b>	
	Rett Communication Guidelines. <b>Gillian TOWNEND</b> (Royaume-Uni) Speech therapy interventions and Alternative and Augmentative Communication (AAC) in Rett syndrome. <b>Stéphane JULLIEN</b> (Suisse)	Plénière 1
	11:00 - 12:30 <b>MEDICAL AND PARAMEDICAL SUPPORT 2</b>	
	Physical therapy. <b>Meir LOTAN</b> (Israël) Motricity. <b>Meir LOTAN</b> (Israël)	Plénière 2
	12:30 - 13:30 <b>LUNCH COCKTAIL</b>	
	13:30 - 15:00 <b>MEDICAL AND PARAMEDICAL SUPPORT 1</b>	
	AAC in Rett syndrome. <b>Anne-Laure ZILIOX</b> (France), <b>Maryline POUETO</b> (France) Advanced technologies for cognitive and motor telerehabilitation in Rett Syndrome: Amelie and Tele-Airett. <b>Martina SEMINO</b> (Italy), <b>Michela PERINA</b> (Italy)	Plénière 1
	13:30 - 15:00 <b>MEDICAL AND PARAMEDICAL SUPPORT 2</b>	
	Nutrition and Rett syndrome. <b>Laure SOULEZ-LARIVIERE</b> (France) Orality and Rett syndrome. <b>Laure SOULEZ-LARIVIERE</b> (France)	Plénière 2