

Saturday, September 30, 2023 | Bronx, NY

AGENDA

8:30-9a Arrival & Registration

\*\*Program & speakers subject to change

9-9:15a Welcome

Sasha Jacobs, MD, Director, Tri-State Rett Syndrome Center, Montefiore Medical Center

- 9:15-10a IRSF Family Empowerment & Research Update Paige Nues, Director of Family Empowerment, International Rett Syndrome Foundation
- **10-10:40a** Update from Neurogene Albena Patroneva, MD, MBA, Senior Vice President, Clinical Development
- 10:40-11a BREAK
- 11-11:30a Treating Rett syndrome by restoring MECP2 expression from the inactive X chromosome

Jeannie Lee, MD, PhD, Endowed Chair in Molecular Biology, Massachusetts General Hospital & Professor of Genetics,Harvard Medical School

- 11:30-11:50a A Novel X-Reactivation Genetic Therapy is Highly Efficacious and Shows Superior Biodistribution in Large Animals Cassandra Dennys, PhD, Senior Scientist, Alcyone Therapeutics
- 11:50a-12p X-Reactivation Q&A
- 12-1p LUNCH
- 1-1:45pQuality of Life Along the Lifespan | Parent Panel<br/>Moderated by Dr. Sasha Jacobs
- 1:45-2:15p"Swim Whisperers" Adaptive Swim Methodology<br/>Ailene Tisser, MA, PT, Founder "SWIM ANGELFISH"
- 2:15-2:45p Al-Learners: an Educational Technology Platform that Helps Kids with All Abilities Learn Math Adele Smolansky B.S. Computer Science
- 2:45-3:15p "Yes, We Can Do It" Elaine Keuning MA, CC-SLP, TSSLD, Communication Specialist at the Rett Center at Montefiore

## 3:15-5p Social Reception





