

LEAP Weekend Agenda

Saturday Morning

09.00 - 09.15 Welcome by Reverse Rett Chair of Trustees, John H. Sharpe

09.15 - 10.00 'What regular health assessments are vital for individuals with Rett syndrome at baseline and across the lifespan? Dr Dan Lumsden, Evelina Children's Hospital, London

10.00 - 10.45 Autonomic dysregulation In Rett syndrome-Professor PJ Santosh, CIPP Rett Centre, South London and Maudsley NHS Trust, King's College London.

10.45 - 11.00 Coffee

11.15 - 12.00 Double trouble in Rett syndrome, Jatinder Singh, Ph.D, CIPP Rett Centre, South London and Maudsley NHS Trust, King's College London.

12.00 - 12.45 'Symptoms not to overlook' Panel discussion

Chair: Professor Santosh

Participants: Dr Jay Shetty, Professor Girish Sharma, Dr Dan Lumsden, Dr Katherine Martin, Dr Ram Kumar, Dr Jatinder Singh, Ph.D.

12.45 - 13.30 Lunch

13.30 - 14.15 Emerging treatments for Rett syndrome, Dr Ram Kumar

14.15 - 14.00 Taysha presentation

14.30 - 14.45 Neurogene presentation

14.45 - 15.15 Emerging treatments Q&A

Chair: Professor Siddharth Banka

Participants: Dr Dan Lumsden, Dr Ram Kumar, Professor Santosh, Dr Jay Shetty, Dr Jatinder Singh

15.15 - 15.30 Coffee

15.30 - 16.15 UK Rett syndrome Cost of Illness Model - Faye Bolan, Costello Medical

16.15 - 17.00 Personal Welfare Deputyship - Matthew J Billingsley, Rutters Solicitors

Saturday evening

18.30 - 21.30 - Celebration dinner/dance

Sunday morning

08.00 - 09.30 Special sessions for families and caregivers

Parent's/carer's resilience, health and well-being, Julie Todd CHEK Practitioner and Yoga Teacher and Gary Chambers Reverse Rett Ambassador, Director of Rugby at Warrington Wolves.

09:30 - 09:45 - Opening John Sharpe

09:45 - 10:30 - Presentation of factors leading to respiratory/pulmonary complications in Rett syndrome, Professor Girish Sharma MD., Rush University Medical Centre, Chicago

10:30 - 10:45 - Coffee

10:45 - 11:30 - Prevention and management of pulmonary complications including prevention of aspiration, respiratory insufficiency and need for NIV to treat this, sleep issues which can be helped by NIV use, Professor Girish Sharma MD., Rush University Medical Centre, Chicago

11.30 - 12:15 - Respiratory issues and breathing dysregulation Panel

Chair: Dr Katherine Martin, Nottingham Children's Hospital

Participants: Dr Girish Sharma, Professor PJ Santosh, Dr Ram Kumar, Dr Jay Shetty, Dr Jatinder Singh, Ph.D.

12.15 - 12.30 Closing remarks John Sharpe

12.30 - 13.30 Lunch

13:30 - Depart

