

2015 International Tuberous Sclerosis Complex Research Conference: From Treatment to Prevention

10-12 September 2015, Mercure Windsor Castle Hotel, Windsor, UK

Day One: Thursday 10 September 2015

12:00 - 13:30 Registration and Lunch

13:30 - 14:00 Opening address, aims, objectives and structure for event, NIH update

14:00 – 15:30 Plenary 1: Early diagnosis and the impact of genetics on diagnosis

14:00-14:15 Community/ family speaker

14:15-14:45 Julian Sampson – Genetics and early diagnosis

14:45-15:15 Darcy Krueger – *Is it safe to intervene early?: data on long-term treatment of children with TSC with vigabatrin and mTOR inhibitors*

15:15-15:30 Rebecca Ihrie - The origin of SEGAs

15:30-16:00 Break

16:00 - 17:30 Plenary 2: Impact and gaps of mTOR inhibitor treatment of TSC

16:00-16:30 Chris Kingswood – mTOR inhibitors, where are we now

16:30-16:45 Sophie Thompson - Beyond mTOR

16:45-17:15 David Franz – mTOR inhibitors, where next

17:15-17:30 Jadwiga Schreiber – Toward a better understanding of epilepsy

17:30 - 19:30 Break

19:30 – 21:30 Conference Dinner, keynote speaker Michael Hall

Day Two: Friday 11 September 2015

07:30 - 08:30 Breakfast

08:30 - 10:15 Plenary 3: The potential for preventing epileptogenesis in TSC

8:30-8:45 Community/family speaker

8:45-9:15 Sergiusz Jóźwiak – EPISTOP and other new data on early intervention for epilepsy in TSC

9:15-9:45 Martina Bebin – The potential for early intervention to prevent the onset of epilepsy in TSC

9:45-10:15 Michael Wong – New data on the genesis of epilepsy

10.15 - 10:45 Break

10:45 – 12:30 Plenary 4: Breakthroughs in the understanding of lung and renal manifestations of TSC

10:45-11:00 Carmen Priolo – Aberrant lipid metabolism as a TSC biomarker

11:00-11:30 Wei Shi – A new mouse model of LAM

11:30-12:00 Frank McCormack – mTOR inhibitors and beyond in the lung

12:00-12:30 John Bissler – TSC renal failure and cystic disease

12:30 - 13:40 Lunch and Networking

13:40 – 15:45 Plenary 5: Breakthroughs in understanding the pathogenesis of TSC at the cellular level

13:40-13:50 Community/family speaker

13:50-14:20 Brendan Manning - TSC1B7 or other new data

14:20-14:35Gina Lee – mTORC1-mediated mRNA alternative splicing in TSC and LAM

14:35-15:05 Andy Tee - HIF-1 or other new data

15:05-15:35 John Blenis - Glucose and glutamate metabolism new data

15:35 - 16:00 **Break**

16:00 – 17:00 Plenary 6: Late breaking research

17:15 – 18:15 Poster viewing and drinks reception

Day Three: Saturday 12 September 2015

07:30 - 8:30 Breakfast

08:30-10:00 Plenary 8: Burden of TSC and engaging those affected to impact research

8:30-8:45 Community/family speaker

8:45-9:15 Petrus de Vries – The neuropsychiatric burden and methods that work to lessen the burden

9:15-9:45 Anna Jansen - Burden of TSC & health economics

9:45-10:15 Patrick Bolton – TS2000: the impact of TSC in early years

10.15 - 10:45 Break

10:45-12:30 Plenary 9: Translating research into improvements in care and outcomes

10:45-11:15 David Kwiatkowski – Genetics and potential for personalized medicine

11:15-11:45 Lisa Henske – Treatments on the horizon for TSC and LAM

11:45-12:15 Mustafa Sahin – The potential for early intervention to prevent development of autism

12:15 - 12:30 **Summing Up: Where next?**

12:30 – 13:30 Main Conference Close and Networking Lunch