

TAND

Mini-Symposium

2023



TSC-Associated Neuropsychiatric Disorders (TAND)

PROGRAMME

29 June, 2023 14.00 – 16.30 CET on Zoom

- 14.00 – 14.15** **Welcome:** Prof Anna Jansen (Belgium)
- 14.15 – 14.30** **TANDem Project Update:** Nola Chambers (South Africa)
- 14.30 – 16.30** **Rapid Fire Presentations and Discussions**
- 14.30 – 14.40** **Theme 1 - Pre-clinical TAND Research (Chair: Mustafa Sahin)**
- One mutated allele in the *tsc2* gene is not enough to cause seizures but is responsible for TAND in the zebrafish model of Tuberous Sclerosis Complex (*Olga Doszyn, Justyna Zmorzynska* - Poland)
- 5-minute discussion
- 14.40 - 15.10** **Theme 2 –TAND across the lifespan (Chair: Agnies van Eeghen)**
- Baby Talk in TSC (*Hailey Dollar, Alena Woods, Edina Bene, Kathryn Ryan, Kimbrough Oller, Tanjala Gipson* - USA)
- Tuberous Sclerosis Associated Neuropsychiatric Disorders in adolescents: case series (*Mariana Schwind, Laís Cardozo, Gustava Dória, Ana Pereira and Sérgio Antoniuk* - Brazil)
- How will my child grow up? Adult functioning and childhood predictors in Tuberous Sclerosis Complex: a cross-sectional survey (*Bojana Kerklaan, Annelieke Muller, Agnies van Eeghen* - the Netherlands)
- 15-minute discussion
- 15.10 – 15.15** **5-minute movement break**
- 15.15 – 15.45** **Theme 3 - Understanding aspects of TAND (Chair: Chris Kingswood)**
- Understanding the impact of TSC: Development and validation of the TSC-PROM (*Annelieke Müller, Michiel AJ Luijten, Lotte Haverman, Wendela L de Ranitz-Greven, Peter Janssens, André B Rietman, Leontine W ten Hoopen,*

Laura CG de Graaff, Marie-Claire de Wit, Anna C Jansen, Tanjala Gipson, Jamie K Capal, Petrus J de Vries, Agnies M van Eeghen - the Netherlands)

Understanding and supporting families with TSC-Associated Neuropsychiatric Disorders (TAND) in India (*Shoba Srivastava - India*)

Understanding caregiver experiences of sleep management difficulties in individuals with tuberous sclerosis complex: A qualitative approach (*Stacey Bissel - UK*)

15-minute discussion

15.45 – 16.20

Theme 4 – TAND Intervention and Services Research (Chair: Jamie Capal)

The Role of Developmental and Behavioural Paediatrics in a TSC Clinic (*Alice Bryn Salter Candice Sheldon, Susan Markle, Klaus Werner - USA*)

The Assessment and Treatment of Behaviour Problems in TSC: A Telehealth Approach (*Nicole M. McDonald, Salma Peña, Camila Ferrario, and Karolina Grotkowski, USA*)

The DNA-V Model of Acceptance and Commitment Therapy for Young People Living with Tuberous Sclerosis Complex: Study Protocol and Early Findings for an Acceptability and Feasibility Randomised Control Trial (*Alexander Marsh, Katie Powers, Ingram Wright, Sam Amin - UK*)

Well-Beans for Caregivers Programme: Exploring the feasibility, acceptability and potential impact of an ultra-brief online well-being programme for caregivers of children with tuberous sclerosis complex (TSC) in South Africa and the United Kingdom (*Liezl Schlebusch - SA*)

15-minute discussion

16.20 – 16.30

Open discussion and closing (Prof Petrus de Vries)