

eSNORE research update for caregivers and professionals

09:30am – 1:00pm UK  
28<sup>th</sup> September 2021



The Baily Thomas Charitable Fund



FREE ONLINE RESEARCH EVENT



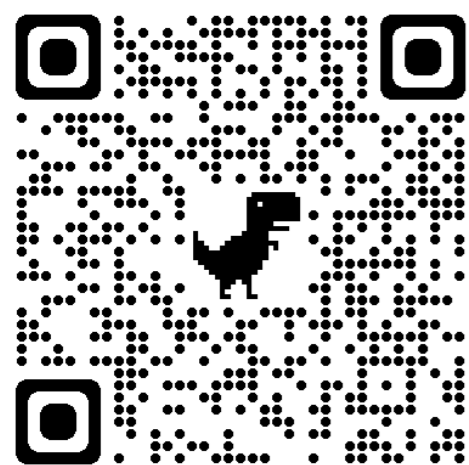
## Sleep in genetic syndromes and clinical considerations

09:30am – 10:15am UK



**Dr Georgie Agar** is a Postdoctoral Research Fellow at the Richards Lab, University of Birmingham. Georgie's research interests include sleep difficulties and mitigating against negative outcomes for people with intellectual disability. She leads work on the Sleep-Impulsivity-Behaviour project, which aims to improve understanding of sleep and executive functioning in relation to self-injurious behaviour in children with autism and intellectual disability. Dr Agar's PhD work was funded by Cerebra, with a focus on developing novel methodologies for assessing poor sleep in individuals with rare genetic syndromes associated with intellectual disability.

**Dr Catherine Hill** is an Associate Professor of Child Health and Honorary Consultant Paediatrician in Sleep Medicine at the University Hospital Southampton. She has worked in the field of children's sleep medicine since 1995 and her work has involved several vulnerable populations, including children with developmental disorders. Her current and recent research has explored sleep disordered breathing in young children with Down syndrome and movement disorders in sleep. Dr Hill is a co-Investigator on the eSNORE project.



Please register for the event and submit questions for this session via the QR code or website address



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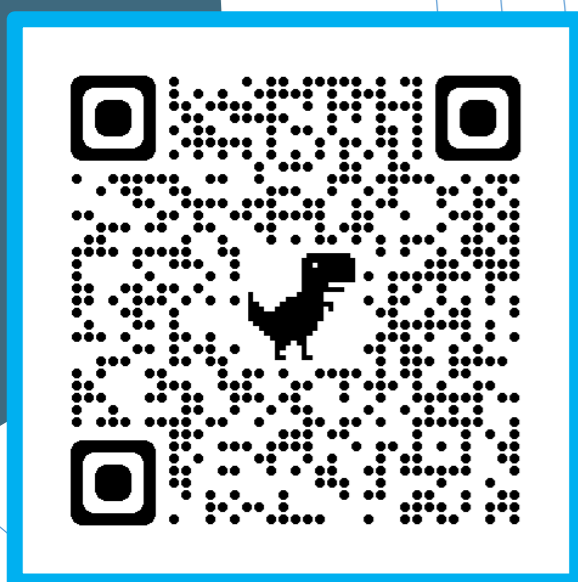


## TSC research findings from eSNORE and the Cerebra Network

10:30am – 11:15am UK



**Dr Caroline Richards** is a Senior Lecturer in Neurodevelopmental Disorders, a Clinical Psychologist, and Research Lead for the Cerebra Network for Neurodevelopmental Disorders based at the University of Birmingham. Her research focuses on reducing negative clinical outcomes for children. Dr Richards leads a programme of sleep research to understand why sleep problems occur in children with rare genetic syndromes, and help families to find solutions to these sleep difficulties. Dr Richards is the Principal Investigator of the eSNORE project.



**Dr Stacey Bissell** is a Cerebra-funded Postdoctoral Research Fellow at the Richards Lab and Cerebra Network for Neurodevelopmental Disorders, University of Birmingham. Her research focuses on sleep and behaviour in tuberous sclerosis complex (TSC) and factors associated with poor sleep in children with rare genetic syndromes associated with intellectual disability. Dr Bissell is the Research Lead for the eSNORE project. She is also the Research Lead for the sleep and eating behaviour cluster as part of the TSC-associated neuropsychiatric disorders (TAND) consortium for the TANDem project.



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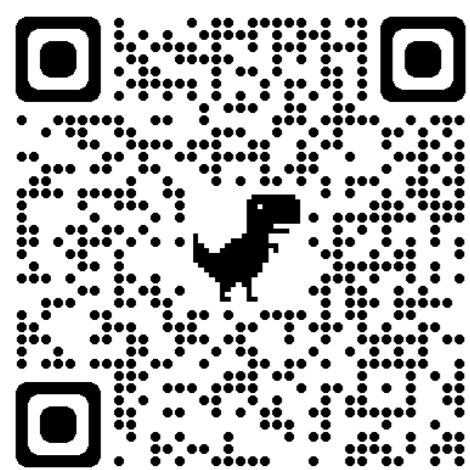


## Sleep in the context of TAND and the TANDem project 11:30am-12:15pm UK

**Professor Petrus J de Vries** is the Professor of Child and Adolescent Psychiatry and Founding Director for Autism Research in Africa (CARA) at the University of Cape Town. He has a longstanding clinical research programme in tuberous sclerosis complex (TSC) and its TSC-associated neuropsychiatric disorders (TAND). He was the chairman of the International Neuropsychiatry Panel that coined the term TAND and is co-author of the TAND Checklist. In 2014 he was awarded the Manuel R Gomez Award for his contributions to TSC. Professor de Vries is Principal Investigator of the TANDem project (Empowering Families through Technology: A mobile-health project to reduce the TAND identification and treatment gap) and is a co-Investigator of the eSNORE project.



**Dr Stephanie Vanclooster** is a Clinical Psychologist and Postdoctoral Researcher at Vrije Universiteit Brussel, Belgium. She is currently the Postdoctoral Researcher for the TANDem project, where she co-leads the cluster group focusing on quality of life, burden of illness and psychosocial aspects related to TSC-associated neuropsychiatric disorders (TAND). Together with Dr Stacey Bissell, she conducted a scoping review on existing TAND research, to identify knowledge gaps and set up future research lines in relation to TAND.



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