

Conference Program

Saturday 20 November 2021



The first updates to the International TSC Management and Surveillance Guidelines since 2013 have just been published. Many of the updates are in the area of TAND - TSC-Associated Neuropsychiatric Disorders, which are often the most difficult symptoms of TSC to cope with. The virtual event provides an opportunity to hear from two international experts in this field – Psychiatrist Professor Petrus de Vries and Paediatric Neurologist Professor Anna Jansen.

The Perth event will also include expert in person presentations and the opportunity to connect and discuss a number of other key issues affecting people living with TSC.



Professor Petrus de Vries, Sue Struengmann
Professor of Child & Adolescent Psychology,
University of Cape Town



Professor Anna Jansen, Head of Paediatric
Neurology, University Hospital Antwerp, Belgium

Times shown are WA time unless stated otherwise



In-Person in WA – Subiaco Room, Ground Floor, Four Points by Sheraton Hotel, 707 Wellington Street, Perth, WA

8.45am REGISTRATION, WELCOME TEA AND COFFEE

Genetics and TSC

Facilitator: Belinda Honess, Stepping Stones, WA

9.00am Acknowledgement of Country & Conference Welcome
Nicole Stone, TSA's Regional Contact for WA

9.05am TSC Community Speaker
Lisa Anfusio, mum of Jacob who lives with TSC

9.15am Genetics and TSC
Dr Kaitlin McGinnis, Advanced Trainee in Clinical Genetics and General Paediatrics, Genetic Services, WA

9.45am COMFORT BREAK



VIRTUAL Event via Zoom

The Updated TSC Surveillance and Management Guidelines

Facilitator: Rob Rossano, father of Roxie, who lives with TSC

10.00am	NT 11.30am QLD 12.00pm SA 12.30pm NSW/ACT/VIC/TAS 1.00pm NZ 3.00pm	Acknowledgement of Country & Virtual Conference Welcome Jackie Gambrell, General Manager, TSA
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10.05am	NT 11.35am QLD 12.05pm SA 12.35pm NSW/ACT/VIC/TAS 1.05pm NZ 3.05pm	The International TSC Surveillance and Management Guidelines – what has changed and why? Dr Darcy Krueger, Director of the Tuberous Sclerosis Clinic and Associate Professor of Clinical Paediatrics and Neurology at Cincinnati Children's Hospital Medical Center
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TAND

10.30am	NT 12.00pm QLD 12.30pm SA 1.00pm NSW/ACT/VIC/TAS 1.30pm NZ 3.30pm	Introducing TAND – what do we mean by TAND and how does it present? Professor Petrus de Vries, Sue Struengmann Professor of Child & Adolescent Psychiatry, University of Cape Town, South Africa
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11.15am TEA, COFFEE AND COMFORT BREAK

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11.30am	NT 1.00pm QLD 1.30pm SA 2.00pm NSW/ACT/VIC/TAS 2.30pm NZ 4.30pm	Managing TAND – the new clinical guidelines for identifying and treating TAND, latest research, the TANDem Project and the TAND app Professor Anna Jansen, Head of Paediatric Neurology, University Hospital Antwerp, Belgium and Professor Petrus de Vries, Sue Struengmann Professor of Child & Adolescent Psychiatry, University of Cape Town, South Africa
12:30pm	NT 2.00pm QLD 2.30pm SA 3.00pm NSW/ACT/VIC/TAS 3.30pm NZ 5.30pm	Zoom Question Time
1.00pm	NT 2.30pm QLD 3.00pm SA 3.30pm NSW/ACT/VIC/TAS 4.00pm NZ 6.00pm	VIRTUAL Event via Zoom CLOSSES



In person in WA – Subiaco Room, Ground Floor, Four Points by Sheraton Hotel, 707 Wellington Street, Perth, WA

1.00pm **LUNCH** – The Eatery Restaurant, Ground Floor, Four Points by Sheraton Hotel

Living with TSC

Facilitator: Belinda Honess, Stepping Stones, WA

2.00pm	Session A: Epilepsy and TSC – Subiaco Room Professor Lakshmi Nagarajan, Neurologist/Epileptologist, Perth Children's Hospital	Session B Discussion group: How does TSC change as we age? – The Bar Area Facilitated by Dr Hemant Kulkarni, Nephrologist, Royal Perth Hospital and Wexford Medical Centre - Murdoch
2.45pm	Supports and services that are available from Tuberous Sclerosis Australia (TSA)	
3.00pm	My advocacy story Belinda Honess, Stepping Stones, WA	
3.15pm	Epilepsy Action Australia and the services we offer in WA	
WORKING TEA, COFFEE AND COMFORT BREAK		
3.20pm	Small discussion groups: 'What is your experience of health and support services in WA?'	
3.45pm	Panel discussion led by Professor de Vries with questions from the audience 'How do we find services and create pathways to services here in WA?' Panel: Dr Fiona McKenzie (Geneticist), Dr Hemant Kulkarni (Nephrologist), Professor Lakshmi Nagarajan (Neurologist), Professor Anna Jansen (Neurologist), Professor Petrus de Vries (Psychiatrist)	
4.30pm	SOCIAL HOUR in The Bar, Ground Floor, Four Points by Sheraton Hotel	
In person WA Event CLOSSES		

TSA would like to thank all speakers, facilitators and participants at the TAND+ Conference 2021.

TSA would also like to acknowledge that the Conference has been made possible thanks to the generosity of the following sponsors:

