



Saturday 15 May 2021	
1pm	Session 1: What we know about TSC in 2021
1pm	Acknowledgement of Country
1.10pm	Conference Welcome TSC Community Speaker: Lynn Wilson, Founder TSA, NSW
1.20pm	KEYNOTE: What we now know about TSC including the latest global research and treatments Dr Darcy Krueger, Director of the Tuberous Sclerosis Clinic and Associate Professor of Clinical Paediatrics and Neurology at Cincinnati Children's Hospital Medical Center, USA
BREAK	
2.30pm	Session 2: Epilepsy and TSC
2.30pm	Our family's epilepsy journey TSC Community Speaker
2.35pm	Clinical management of epilepsy in TSC Dr Katherine Howell, Paediatric Neurologist, Royal Children's Hospital, Melbourne, VIC Dr John Lawson, Paediatric Neurologist and Co-Director TSC Clinic, Sydney Children's Hospital, NSW Dr Kate Riney, Paediatric Neurologist & Epileptologist and Lead Clinician, Queensland Children's Hospital, QLD
BREAK	
4.00pm	Session 3: Global Awareness Day and our TSC community
4.00pm	Celebrating TSC Global Awareness Day (GAD) Kate Garrard, Fundraising and Communications Lead, TSA
4.15pm	Networking/small discussion groups (by geographical location including a group for TSCNZ) "Where and how can we get the support we need where we live in Australia or New Zealand?"
END OF DAY ONE	



Sunday 16 May 2021			
9.00am	Session 4: Skin and Kidney symptoms and treatment		
9.00	Welcome		
9.10	Living with TSC from a sister's perspective TSC Community Speaker		
9.15	Skin issues in TSC including an update on the latest angiofibroma research trials in Australia and New Zealand Dr Caroline Mahon, Dermatologist, Christchurch Hospital, New Zealand		
9.45	TSC-related kidney issues TSC Community Speaker		
9.50	Identifying, treating and managing TSC-related kidney issues Dr Sean Kennedy, Nephrologist, Sydney Children's Hospital Randwick and School of Children and Women's Health, NSW		
BREAK			
10.30am	Session 3: TSC surveillance and delivery of healthcare in the COVID era		
10.30	Our family's experience of telehealth TSC Community Speaker		
10.35	TSC Surveillance in the COVID era and our evolving use of telehealth Dr David Mowat, Head of Genetics and Co-Director TSC Clinic, Sydney Children's Hospital, NSW encourages members of the TSC Virtual Conference Steering Committee share their experiences, observations and thoughts on where to next		
11:10	Using the TAND checklist TSC Community Speaker		
11.20	Tools and apps for delivering healthcare Clara Chung, Clinical Geneticist, Sydney Children's Hospital, NSW		
11.30	<table><tr><td>How TSA can help and support you Jackie Gambrell, General Manager TSA</td><td>How TSCNZ can help and support you Helen Willacy, President, TSCNZ</td></tr></table>	How TSA can help and support you Jackie Gambrell, General Manager TSA	How TSCNZ can help and support you Helen Willacy, President, TSCNZ
How TSA can help and support you Jackie Gambrell, General Manager TSA	How TSCNZ can help and support you Helen Willacy, President, TSCNZ		
11.40	Networking/small discussion groups (including a group for TSCNZ) What TSA or TSCNZ services have you found useful and/or what else do you want or need?		
12.00	Report back from discussion groups		
12.15	Conference Close		
12.30	OFFICIAL CLOSE OF CONFERENCE		

Note: this program is not yet final and is subject to change