

Community Connect 2024

A chance to connect, learn and share.

Saturday 23rd March
Colombo Building, UNSW,
High Street, Randwick, Sydney

This event is proudly hosted by



9.30	ARRIVAL AND REGISTRATION	Foyer, Colombo Building
10.00	Welcome, Jackie Gambrell, CEO, TSA Introduction to today's event	Colombo Theatre B
10.05	TSC Community speaker, Debbie Crosby, NSW Regional Coordinator TSA and Alana's mum My family's experience of living with TSC	
10.15	Genetics and TSC, Dr Clara Chung, Clinical Geneticist, Sydney Children's Hospital <ul style="list-style-type: none"> • What causes TSC? • How TSC is diagnosed? • <i>TSC1</i> and <i>TSC2</i> • The mTOR pathway • How is TSC inherited in families? • The role of genetic testing 	
10.45	Surveillance and Management of TSC, Dr Denise Chan, Paediatric Neurologist, Sydney Children's Hospital and Dr Zebunnessa Rahman, Epileptologist/Neurologist, Westmead Hospital <ul style="list-style-type: none"> • Why surveillance and monitoring is so important for people living with TSC • What are the most important aspects in childhood? • What are the likely changes during the lifespan? • What are the most important aspects as adults? 	
11.15	Recent advances in the management of facial angiofibromas, A/Professor Deshan Sebaratnam, Dermatologist, Liverpool Hospital	
11.30	MORNING TEA BREAK	Foyer, Colombo Building
12.00	STREAM A: Colombo Theatre B Of most interest to family members/ carers of children living with TSC	STREAM B: Colombo LG01 Of most interest to adults living with TSC and family members/carers of adults living with TSC
	TSC Community speaker, Miia Groenewald, Oskar's mum Oskar's epilepsy	The kidneys and TSC, Dr Sean Kennedy, Nephrologist, Sydney Children's Hospital <ul style="list-style-type: none"> • How TSC can affect the kidneys

TSA would like to thank all the speakers and health care professionals for so generously donating their time and expertise at this event. We also thank the Department of Social Services and AFT Pharmaceuticals for their generous financial support.



12.15	<p style="text-align: right;">Colombo Theatre B</p> <p>TSC and epilepsy, Dr Denise Chan, Paediatric Neurologist, Sydney Children's Hospital</p> <ul style="list-style-type: none"> • Antenatal monitoring • Infantile spasms • Seizures • Epilepsy management options • Refractory epilepsy <p>Epilepsy Surgery, Dr Erica Jacobson and Dr Ruth Mitchell, Epilepsy Neurosurgeons, Sydney Children's Hospital</p> <ul style="list-style-type: none"> • Question and answer session 	<p style="text-align: right;">Colombo LG01</p> <p>Panel discussion: Dr Sean Kennedy, Nephrologist, Sydney Children's Hospital and Dr Gopi Rangan, Nephrologist, Westmead Hospital</p> <p>Facilitated by Katrina Watt, TSA Telehealth Nurse</p> <ul style="list-style-type: none"> • Your chance to ask the doctors your questions on the kidneys and TSC
1.00	<p>LUNCH BREAK Foyer, Colombo Building</p>	
	<p>STREAM A: Colombo Theatre B Of most interest to family members/ carers of children living with TSC</p>	<p>STREAM B: Colombo LG01 Of most interest to adults living with TSC and family members/carers of adults living with TSC</p>
2.00	<p>TSC Community speaker, Clarissa Tuia, Mase's mum</p> <p>Mase's story</p>	<p>TSC Community speaker, Penny McKee</p> <p>Living with LAM and TSC</p>
2.15	<p>TAND and behavioural issues in children, Dr Vanessa Sarkozy, Developmental and Behavioural Psychologist, Sydney Children's Hospital</p> <ul style="list-style-type: none"> • What is TAND? • The TAND Checklist • Milestones and surveillance at different stages of a child's life • Pathways from concerns to assessment 	<p>VIDEO: TSC and the lungs, Dr Deborah Yates, Respiratory Physician, St Vincent's Hospital</p> <ul style="list-style-type: none"> • How TSC can affect the lungs • Signs and symptoms • Living with and managing LAM <p>2.45 Discuss and share your experiences of the health care system.</p> <ul style="list-style-type: none"> • What are some of the challenges you have faced? • What do you think the 'best' model of care would be for you as an adult living with TSC?
3.15	<p>Jackie Gambrell, CEO, TSA Colombo Theatre B</p>	
	<p>Connect time and AFTERNOON TEA Foyer, Colombo Building</p> <p>Discuss and share your experiences of living with TSC</p> <ul style="list-style-type: none"> • What are some of the challenges you have faced? • What strategies for managing and coping have you successfully used that you can share to help other people here today? 	
4.15	<p>CLOSE OF EVENT</p>	

TSA would like to thank all the speakers and health care professionals for so generously donating their time and expertise at this event. We also thank the Department of Social Services and AFT Pharmaceuticals for their generous financial support.