

TSC Conference 2020: Community Stream

Saturday 2 and Sunday 3 May 2020

Program information

This two-day meeting is for all those affected by TSC, including adults, families and carers. It examines the care of individuals with tuberous sclerosis complex (TSC) and related diseases from various perspectives.

This conference provides a unique opportunity for TSC-affected families and adults to hear from and ask questions of expert TSC health professionals who are leaders in the identification and treatment of this disease.

The event will provide expert knowledge and practical information for all TSC-affected individuals and their families and carers. The 2020 conference will include discussion of:

- clinical developments and new research
- managing different presentations of TSC
- managing behavioural and psychological issues associated with TSC
- fertility and adolescence
- discussion on ways of improving the management of TSC in Australia.

It is also a unique opportunity for those affected by TSC to connect not only with expert health professionals but also with other members of their TSC community.



TSC Community Stream: DAY ONE			
9:30	Morning tea on arrival		
<i>Opening Session</i>			
10:00	Acknowledgement of Country and Conference Welcome – what’s changed since 2015? <i>Jackie Gambrell, General Manager, TSA and Debbie Cosby, President, TSA</i>		
<i>Understanding TSC</i>			
10:30	Genetics and TSC		
11:00	What if genetic testing cannot find a mutation?		
11:15	Morning tea		
<i>Taking Control: Managing TSC</i>			
11:45	Community Speaker		
12:00	Managing signs of TSC in the kidneys		
12:30	OPTION A Managing LAM	OPTION B Managing the skin and facial angiofibromas	
13:00	Lunch		
14:00	Option A Accessing the National Disability Insurance Scheme (NDIS)	OPTION B TBC	OPTION C Mindfulness
14:45	Afternoon Tea		
15:10	OPTION A Community speaker: Living with TSC epilepsy Managing Epilepsy and TSC SEGAs	OPTION B Thriving, not just surviving – psychological wellbeing and TSC	
16:00	Comfort break		
<i>Health Professionals and Community Streams Combine Improving management of TSC in Australia</i>			
16:10	Models of care for TSC		
16:30	What does improved management of TSC look like to me?		
16:45	Closing Remarks		
17:00	CLOSE		

Social event and opportunity to share thoughts and questions 6.00pm – 8.00pm



TSC Community Stream: DAY TWO	
9:00	Morning tea on arrival
<i>Managing behavioural and psychological issues</i>	
9:00	Management and Surveillance – why do we need the TSC Guidelines?
9:30	Community Speaker: How I manage my TSC
9:45	Discussion and questions
10:00	Psychological factors and TSC – TAND
10:30	Fertility Issues and TSC
11:00	Morning tea
11.20	OPTION A How can you successfully address these issues with adolescents?
	OPTION B (until 12.45) Group share and discussion – living as an adult with TSC
11.50	Managing Challenging Behaviours
12.20	Discussion and questions
12.30	Accessing Mental Health Services in adolescence and beyond?
12:45	Closing Remarks
1:00	Lunch and Close of Event

NOTE: This DRAFT Program is subject to change.