

Family stream of the 2015 Australian Tuberous Sclerosis Conference

Saturday 14th November

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| 8:30 | Morning tea on arrival | |
| | <i>Plenary Session</i> | <i>Chair: Debbie Crosby</i> |
| 9:15 | Opening remarks <i>Debbie Crosby, TSA President and Dr Sean Kennedy, Sydney Children's Hospital</i> Alex's story by <i>Fiona Hiatt</i> Presentation of the Elizabeth Pinkerton Memorial Award by <i>Sue and Ross Pinkerton</i> | |
| 9:40 | Our common goal: improving outcomes for people with TSC <i>Dr Elizabeth Thiele, Neurologist and Director of the Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i> | |
| 10.00 | Break into medical and family streams | |
| 10:10 | Genetics of TSC <i>Dr Chirag Patel, Clinical Geneticist, Queensland Clinical Genetics</i> | |
| 10:50 | Getting to know you <i>Facilitated by Sue Hawkins, Psychologist</i> | |
| 11:20 | Understanding TSC management guidelines, mTOR inhibitors and TS Cure <i>Dr David Mowat, Clinical Geneticist, Sydney Children's Hospital</i> | |
| 11:50 | From blue book to TAND, screening for developmental and behavioural challenges through a lifetime with TSC <i>Dr Vanessa Sarkozy, Developmental Paediatrician, Sydney Children's Hospital</i> | |
| 12:30 | Lunch | |
| 1:15 | Annual general meeting of Tuberous Sclerosis Australia | |
| 1:45 | Navigating Mental Health Services: Short cut through the maze! <i>Dr Bill Papakostas and Leslie Pullen, Headspace</i> | |
| 2:15 | Understanding and diagnosing TSC Associated Neuropsychiatric Disorders (TAND) <i>Lisa Underwood, PhD, Research Fellow, University of Auckland</i> | |
| 2:30 | TS2000: TAND research from the UK <i>Dr Charlotte Tye and Dr Patrick Bolton, King's College London, Institute of Psychiatry, Psychology & Neuroscience</i> | |
| 3:00 | Afternoon tea | |
| | <i>Session A: For parents and carers of a child with TSC</i> | <i>Session B: For adults living independently with TSC</i> |
| 3:20 | Understanding the out of pocket costs faced by families with a child with TSC <i>A/Prof Yvonne Zurynski, Australian Paediatric Surveillance Unit</i> | Group discussion led by <i>Sue Hawkins, Psychologist</i> |
| 3:30 | Trapeze – Supporting young people to make the leap into adult health <i>Madeleine Bridgette, Manager, Trapeze</i> | |
| | <i>Sessions combine</i> | |
| 4:00 | Managing the signs of TSC on the skin <i>Dr Anne Halbert, Dermatologist, Princess Margaret Hospital, Perth</i> | |
| 4:30 | Close | |

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Sunday 15th November

| | | |
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| 9:00 | The signs and symptoms of TSC in the brain <i>Dr Elizabeth Thiele, Director, Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i> | |
| 9:45 | Managing epilepsy in TSC, an Australian perspective <i>Dr Simone Ardern-Holmes, Paediatric Neurologist, Westmead Children's Hospital</i> | |
| 10:30 | Discussion | |
| 10:45 | Morning tea | |
| 11:00 | My TSC and LAM story <i>Bree Dixon</i> | |
| 11:10 | Research in TSC and LAM. Achievements and future directions <i>Dr Lisa Henske, Director, Centre for LAM Research and Clinical Care, Brigham and Women's Hospitals, Boston</i> | |
| 12:10 | Managing signs of TSC and LAM in the kidneys <i>A/Prof Nikky Isbel, Nephrologist, Princess Alexandra Hospital</i> | |
| 1:00 | Lunch | |
| | <i>Session A: TSC – Colombo House Theatres</i> | <i>Session B: TSC – LAM – Quadrangle Room 1001</i> |
| 1:45 | Less common signs and symptoms of TSC <i>Dr Elizabeth Thiele</i> | Diagnosis and management of LAM <i>Prof Allan Glanville, Medical Director Lung Transplantation, Director Thoracic Medicine, St Vincent's Hospital Sydney</i> |
| 2:15 | Small group questions – round 1 <i>Choose from either:</i> <i>Neurology – Dr Elizabeth Thiele and Dr Simone Ardern Holmes</i> <i>Genetics – Dr David Mowat</i> <i>Kidneys – Dr Murray Leikis, Nephrologist, Wellington Hospital</i> | LAM Research in Australia <i>Dr Brian Oliver, Head Molecular Pathogenesis Group, Respiratory Cellular and Molecular Biology, Woolcock Institute of Medical Research</i> |
| 2:45 | Small group discussions – round 2 <i>(topics repeated)</i> | Discussion <i>With Dr Henske, Prof Glanville, and Dr Oliver.</i> |
| 3.10 | Building a stronger TSC community <i>Clare Stuart and Debbie Crosby</i> | |
| 3:30 | Close and afternoon tea | |

The conference is partially supported by an educational grant from Novartis Pharmaceuticals. Novartis have provided no input to the content of the conference.



We are grateful to these organisations for making this weekend possible

2015 Conference Dinner Sponsor

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The Conference is supported by an Educational Grant from

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Registration form – Family stream of the 2015 Australian Tuberos Sclerosis Conference

The family stream is intended for people with TSC, their caregivers, family and friends. You can use this form to register for the conference and pay by credit card. You can also use this form to apply for a travel grant to attend the conference.

If you have any difficulties or are not able to pay with a credit card, please contact Clare Stuart (clare@tsa.org.au or 0410 685 181).

Please register by Friday 6th November as registration fees will increase after this date.

Cancellations and Refunds

Cancellation must be made in writing or via email.

To avoid disappointment and to assist with catering numbers please register by Friday 6 November 2015. A refund will be issued for any cancellations received in writing or email prior to this date or if a replacement is nominated.

First Name _____ Last Name _____

Email Address _____

Names of any additional people you would like to register _____

Registration type *Please enter number of people for each option*

_____ @ \$70 Saturday and Sunday

_____ @ \$45 Saturday only

_____ @ \$45 Sunday only

plus conference dinner by the beach _____ @ \$55 per person

Total registration fees _____

Payment option I will pay by MasterCard

I will pay by Visa

Card Number _____

Security Code _____ Expiry (mm/yy) _____

Card first name _____ Card last name _____

Street Address _____

City _____ State _____ Postcode _____

Country _____

Please turn over for additional registration information and travel grant application

Any special requirements (including dietary and access) _____

Do you give us permission to use photographs of you taken at the event? Yes No

Do you give us permission to provide your name and email address to fellow conference participants in the family stream? Yes No

Are there any particular areas of interest you are looking forward to hearing about at the conference? _____

What are the ages of the TSC affected people in your family? _____

Travel grant application

Tuberous Sclerosis Australia offers travel grants to cover part of the cost of travel to the conference. The federal government has not provided funding for this in 2015 so the funding available is more limited than at prior events. We encourage you to apply for travel funding if you require this to attend the conference. We also encourage you to stay with friends or family in Sydney if possible to minimise costs.

Please read the travel grant information at

<https://tsa.org.au/wp-content/uploads/2015/08/Travel-grant-information.pdf>

Would you like to apply for a travel grant to assist with the cost of your travel to the conference? Yes No

Travel grants are for individuals with TSC and their families.

Method of travel _____

Please estimate the cost of your travel _____

Yes, I have read the travel grant information at

<https://tsa.org.au/wp-content/uploads/2015/08/Travel-grant-information.pdf>