

# 2015 Australian Tuberous Sclerosis FAMILY & MEDICAL CONFERENCE

## UNIVERSITY OF NEW SOUTH WALES, SYDNEY

Scientific program will include new management approaches and other practice-changing research in Tuberous Sclerosis (TSC) and Lymphangioleiomyomatosis (LAM). Health professionals from around Australia will share their expertise alongside Drs Henske and Thiele.

**MEDICAL STREAM**

14TH NOVEMBER

**FAMILY STREAM**

14TH & 15TH NOVEMBER

## GUEST SPEAKERS



### Elizabeth Henske

Dr. Elizabeth (Lisa) Henske is the founding Director of the Center for LAM Research and Clinical Care at the Brigham and Women's Hospital in Boston MA. The Henske research laboratory is focused on the cellular and molecular mechanisms through which mutations in the Tuberous Sclerosis Complex (TSC) genes lead to TSC and LAM.

Lisa's discoveries have revolutionised our understanding of both TSC and LAM and her current work on the next phase of TSC research will inspire attendees with hope for a future cure for TSC and LAM.

### Elizabeth Thiele

An experienced neurologist and epileptologist, Dr Elizabeth Thiele is the Director of the Paediatric Epilepsy Program and the Director of the Herscot Centre for Children and Adults with Tuberous Sclerosis Complex at Massachusetts General Hospital. Elizabeth's extensive research on epilepsy and TSC allows her to offer fresh perspectives on the care of patients of all ages with Tuberous Sclerosis.



### Steering Committee Members

**Sean Kennedy** - Sydney Children's Hospital • **Vanessa Sarkozy** - Sydney Children's Hospital  
**Kate Riney** - Lady Cilento Children's Hospital, Brisbane • **Deborah Yates** - St Vincent's Hospital Sydney  
**Nikky Isbel** - Princess Alexandra Hospital, Brisbane

For more information visit: [tsa.org.au/2015-conf](http://tsa.org.au/2015-conf) or email: [clare@tsa.org.au](mailto:clare@tsa.org.au)

## Australian Tuberous Sclerosis Conference

# Medical Stream

14<sup>th</sup> November 2015 9am to 4:30pm

Colombo Theatres, The University of New South Wales,  
Sydney

### Program information

This one day meeting is for professionals from all disciplines. It examines the care of individuals with tuberous sclerosis (TSC) and related diseases from various perspectives, including three key sessions:

- Intergenerational issues
- Beyond the guidelines
- Improving management of TSC in Australia

This conference provides a unique opportunity for those interested in TSC to share experiences and ideas for improving care for people with TSC while understanding how research into TSC impacts on other diseases including **epilepsy, autism, kidney tumours and cancer**.

A conference dinner will be held on Saturday evening combined with the family conference.

### Registration

Cost to attend is \$100, which includes morning tea, lunch and afternoon tea. Junior medical staff, medical students, nurses and allied health professionals are eligible for a discounted rate of \$20. These fees help to off-set the cost of the meeting to Tuberous Sclerosis Australia.

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 prior to this date or if a replacement is nominated.

Please register online at [www.tsa.org.au/2015-conf](http://www.tsa.org.au/2015-conf)

### For more information

Please contact Clare Stuart, General Manager, Tuberous Sclerosis Australia  
+ 61 410 685 181 or [clare@tsa.org.au](mailto:clare@tsa.org.au)

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



## Program as at 19 October 2015

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|--------------|--|
| <b>8:30</b>  | <b>Morning tea on arrival</b>  |
|              | <i>Plenary Session</i> <i>Chair: Debbie Crosby</i>   |
| <b>9:15</b>  | Opening remarks<br><i>Debbie Crosby, TSA President</i><br><i>Including Alex's TSC Story, Fiona Hiatt</i>   |
| <b>9:40</b>  | Our common goal: improving outcomes for people with TSC<br><i>Dr Elizabeth Thiele, Neurologist and Director of the Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i>   |
|              | <i>Session: Intergenerational aspects of TSC</i> <i>Chair: Dr Deborah Yates</i>  |
| <b>10:10</b> | Genetics across the lifetime<br><i>Dr David Mowat, Clinical Geneticist and TSC Clinic Co-director, Sydney Children's Hospital</i>  |
| <b>10:30</b> | Managing infants with TSC and at risk of TSC<br><i>Dr Kate Riney, Paediatric Neurologist and TSC Clinic Director, Lady Cilento Children's Hospital, Brisbane</i>   |
| <b>10:45</b> | Understanding LAM and TSC across a lifetime<br><i>Dr Lisa Henske, Director, Centre for LAM Research and Clinical Care, Brigham and Women's Hospitals, Boston</i><br><i>With Dr Deborah Yates, Respiratory Physician, St Vincent's Hospital, Sydney.</i>  |
| <b>11:10</b> | Impact of mTOR-I on fertility<br><i>A/Prof Nikky Isbel, Nephrologist, Princess Alexandra Hospital</i>  |
| <b>11:30</b> | Reproductive technologies: presenting options for people with TSC, LAM and other genetic disorders<br><i>Prof Bill Ledger, Obstetrics &amp; Gynaecology, Royal Hospital for Women</i>  |
| <b>11:50</b> | Psychological factors for families living with TSC and LAM<br><i>Kay Wilhelm, Liaison Consultation Psychiatry St Vincent's Hospital</i>  |
| <b>12:10</b> | Discussion and questions   |
| <b>12:30</b> | <b>Lunch</b>   |
|              | <i>Session: Beyond the guidelines</i> <i>Chair: Dr Vanessa Sarkozy</i>   |
| <b>1:15</b>  | Less common phenotypes of TSC<br><i>Dr Elizabeth Thiele, Neurologist and Director of the Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i>   |
| <b>1:45</b>  | Research directions in TSC, LAM, mTOR and beyond<br><i>Dr Lisa Henske, Director, Centre for LAM Research and Clinical Care, Brigham and Women's Hospitals, Boston</i>  |
| <b>2:15</b>  | Managing TSC in the era of mTOR inhibitors<br>International perspective – <i>Dr Elizabeth Thiele, Director, Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i><br>Australian perspective – <i>Dr John Lawson, Paediatric Neurology and TSC Clinic Co-director, Sydney Children's Hospital</i><br>Discussion – <i>Chair, Dr Sean Kennedy, Nephrologist, Sydney Children's Hospital</i> |
| <b>3:15</b>  | <b>Afternoon tea</b>   |

| <i>Session: Where to from here?      Chair: Dr Sean Kennedy</i> |  |
|---|--|
| <b>3:30</b>   | <p>TS Cure and opportunities for Australian researchers<br/> <i>Dr David Mowat, Clinical Geneticist and TSC Clinic Co-director, Sydney Children's Hospital</i></p>   |
| <b>3:40</b>   | <p>The importance of coordinated care<br/> <i>TSC parent</i></p>   |
| <b>3:50</b>   | <p>Identifying TSC-associated neuropsychiatric disorders – using the TAND check list<br/> <i>Dr Vanessa Sarkozy, Developmental Paediatrician, Sydney Children's Hospital</i><br/> Vanessa Sarkozy</p>  |
| <b>4:00</b>   | <p>Panel Discussion: How can we improve care for people with TSC?<br/> <i>Dr Lisa Henske, Director, Centre for LAM Research and Clinical Care, Brigham and Women's Hospitals, Boston</i><br/> <i>A/Prof Nikky Isbel, Nephrologist, Princess Alexandra Hospital</i><br/> <i>Dr David Mowat, Clinical Geneticist and TSC Clinic Co-director, Sydney Children's Hospital</i><br/> <i>Dr Kate Riney, Paediatric Neurologist and TSC Clinic Director, Lady Cilento Children's Hospital, Brisbane</i><br/> <i>Clare Stuart, General Manager, Tuberous Sclerosis Australia</i><br/> <i>Dr Elizabeth Thiele, Neurologist and Director of the Carol and James Herscot Center for Tuberous Sclerosis Complex, Massachusetts General Hospital</i></p> |
| <b>4:30</b>   | <b>Close</b>   |

## Registration form – Medical stream of the 2015 Australian Tuberos Sclerosis Conference

The medical stream is intended for health professionals including medical specialists, nursing and allied health professionals.

You can use this form to register for the conference and pay by credit card or have an invoice sent to you.

If you have any difficulties please contact Clare Stuart (clare@tsa.org.au or 0410 685 181).

### 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 \_\_\_\_\_

Institution \_\_\_\_\_

Registration type  \$100 Full day registration  
 \$20 Junior medical staff, trainees, nurses and allied health

Payment option  I require an invoice for payment by my institution  
 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 \_\_\_\_\_

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 medical stream*?  Yes  No