

## CONFERENCE AGENDA

*Draft as of April 2018 (All speakers invited and subject to change)*

### Wednesday, July 25, 2018

2 to 6 p.m.

TSC Consensus Guidelines Update, By invitation only, *Presidential Suite*

6 to 9:30 p.m.

TSCi Dinner, By invitation only, *Fleur de Lis A*

### Thursday, July 26, 2018

9:00 a.m. – 2 p.m.

TSCi Workshop, By invitation only, *Fleur de Lis A*

10 a.m. to 11:30 a.m.

TSC Clinic Directors Meeting, By invitation only, *Plum Blossom*

11:30 a.m. to 2:30 p.m.

Nurses Meeting, By invitation only, *Plum Blossom*

Noon to 6 p.m.

General Conference Registration and Day Camp Registration, *Conference Registration Room and Atrium 2*

1 to 5 p.m.

TSC Consensus Guidelines Update, By invitation only, *Presidential Suite*

1 to 5 p.m.

Exhibit Hall Set Up, *Grand Ballroom C*

3 to 4 p.m.

TSC 101 for Newly Diagnosed Individuals or Families, *Fleur de Lis A*  
*Moderators:* Rob and Shannon Grandia  
*Speakers:* Martina Bebin, MD, MPA; Joyce Wu, MD

3 to 5 p.m.

Meet-and-Greet Opportunities:

- Adults with TSC and Spouses, *Jade Pavilion*
  - *Facilitator:* Jake Irby
- Parents/Caregivers of Transitioning Young Adults, *Jade Room*
  - *Facilitator:* Dana Holinka
- Grandparents, *Counter Offer*
  - *Facilitators:* Geri Greenberg, Ted Mastroianni
- Parents of Young Children with TSC (ages 0-13), *Atrium 1*
  - *Facilitator:* Tara Zimmerman
- Social Networking Groups (Inspire, Facebook), *Plum Blossom*
  - *Facilitator:* Debora Moritz
- Teens and Young Adults (ages 13-25), *Fleur de Lis B*

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.



EMPOWERING THE  
GLOBAL TSC COMMUNITY

DALLAS, TX • JULY 26–29, 2018

CO-HOSTED BY



- *Facilitators:* Junior Leaders
- **Adult Siblings, Atrium 2**
  - *Facilitators:* Carlie Russell, Katrina Evanochko

4:30 to 6 p.m.	TSC Biosample Repository and TSC Natural History Database Projects Q&A, <i>Cherry Blossom</i>
6 p.m.	Conference Welcome and Opening Dinner, <i>East Atrium</i> TS Alliance President and CEO Kari Luther Rosbeck, TS Alliance Board Chair Beth Dean, and TSCi Executive Committee Member
7:30 to 9 p.m.	Preclinical Consortium Steering Committee, By invitation only, <i>Presidential Suite</i>
8 to 9:30 p.m.	TSC Biosample Repository and TSC Natural History Database Projects Q&A, <i>Cherry Blossom</i>
8:30 pm	Social for International Attendees, <i>Fleur de Lis A</i>
8:30 p.m.	Adults with TSC Evening Activity, <i>Jade Pavilion</i> <i>Event Leader:</i> Shannon Grandia
8:30 p.m.	TSC Dad's Outing, <i>Gossip Bar</i> <i>Event Leader:</i> Sean Shillinger
8:30 to 11 p.m.	Teen Lounge Open, <i>Fleur de Lis B</i>

### Friday, July 27, 2018

7 to 8:30 a.m.	Breakfast
7:30 a.m. to 5:30 p.m.	Day Camp, <i>Atrium 1 – Check-In: Stemmons Ballroom</i>
8 a.m. to 5 p.m.	Exhibit Hall and TSC Resource Center, <i>Grand Ballroom C</i>
8:30 to 10 a.m.	<b>Conference Opening Session:</b> Global Status of TSC and Consensus Guidelines for Diagnosis, Surveillance, and Treatment, <i>Grand Ballroom D/E</i> <i>Welcome:</i> Kari Luther Rosbeck <i>Moderator:</i> Chris Kingswood, MBBS, MRCP, FRCP <i>Speakers:</i> Anna Jansen, MD, PhD; Darcy Krueger, MD, PhD; Hope Northrup, MD
10 to 10:15 a.m.	BREAK
10:15 to 11:30 a.m.	<b>First Break Out Session</b>  Track A: Seizure Types and Treatments for Infants and Children with TSC, <i>Grand Ballroom D/E</i> <i>Moderator:</i> James Riviello, Jr., MD

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

Speakers: Brenda Porter, MD, PhD; Michal Tzadok, MD;  
Michael Wong, MD, PhD

Track B: Managing Medical Transitions from Childhood to  
Adulthood, *Grand Ballroom A*

Moderator: Luciana Haddad, MD, PhD

Speakers: Peter Crino, MD, PhD; Philippe Major, MD;  
Elizabeth Thiele, MD, PhD

Track C: Kidney Issues and Treatment Options, *Grand Ballroom B*

Moderator: David Ewalt, MD

Speakers: John Bissler, MD; John Hulbert, MD;  
Chris Kingswood, MBBS, MRCP, FRCP

Track D: Other Manifestations: Bone, Liver, Ovarian, Pancreas, Teeth,  
Spine, and Heart, *Plum Blossom*

Moderator: Finbar O'Callaghan, MA MB ChB MSc PhD  
FRCPCH FRCP

Speaker: Steve Sparagana, MD

Panelists: Elizabeth Gosnell, DMD, MS; Brian Grottkau, MD;  
Ray Yeung, MD

GROUP SESSION: Sibling Support Session, *Fleur de Lis A*

Facilitator: Karen Gilmore

11:30 a.m. to 12:30 p.m. LUNCH, *East Atrium*

12:30 to 5 p.m. Teen Lounge Open, *Fleur de Lis B*

12:30 to 1:45 p.m. **Second Break Out Session**

Track A: SEGA and Treatment Options, *Grand Ballroom D/E*

Moderator: Howard Weiner, MD, FACS, FAAP

Speakers: Daniel Curry, MD; Ian Miller, MD; Jonathan Roth,  
MD

Track B: Advocacy in the Education System for Transition into  
Adulthood, *Grand Ballroom A*

Moderator: Dena Hook

Speakers: Jennifer Flinn, EdD; Dena Hook

Track C: LAM, Treatment Options and Clinical Trials, *Grand Ballroom  
B*

Moderator: Joel Moss, MD, PhD

Speakers: Elizabeth Henske, MD; Frank McCormack, MD;  
Susan Sherman, MHA

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

Track D: TAND: Sleep Disorders in TSC, *Plum Blossom*  
*Moderator:* Anna Jansen, MD, PhD  
*Speakers:* Deborah Briggs, MD; Shafali Jeste, MD; Jonathan Lipton, MD, PhD

**MEET THE EXPERTS ROUND TABLE Q&A, *Fleur de Lis A***  
*Moderator:* Linda Lezotte, RN, BSN

1:45 to 2 p.m.

BREAK

2 to 3:15 p.m.

**Third Break Out Session**

Track A: Epilepsy Surgery and New Breakthroughs in Imaging, *Grand Ballroom D/E*  
*Moderator:* Daniel Curry, MD  
*Speakers:* Aria Fallah, MD; Jonathan Roth, MD; Howard Weiner, MD, FACS, FAAP

Track B: \*Long-Term Care Planning: Special Needs Trusts and Guardianship, *Grand Ballroom A*  
*Moderator:* Dena Hook  
*Panelists:* Deanna M. Eble, Esq.; Kelly Piacenti, MA; Theresa Varnet, MSW, JD

Track C: Seizure Management and Impact on Quality of Life, *Grand Ballroom B*  
*Moderator:* Michael Frost, MD  
*Speakers:* Peter Crino, MD, PhD; Jennifer Waldron

Track D: Skin Involvement and Treatment Options, *Plum Blossom*  
*Moderator:* Mary Kay Koenig, MD  
*Speakers:* Tom Darling, MD, PhD; Joyce Teng, MD, PhD

GROUP SESSION: Women's Health Issues and Reproduction Decision Making for Young Adults, *Fleur de Lis A*  
*Speakers:* Elizabeth Henske, MD; Hope Northrup, MD

3:15 to 3:45 p.m.

BREAK

3:45 to 5:15 p.m.

**General Session:** Research 101: The Path to New Drugs for TSC, *Grand Ballroom D/E*  
*Moderator:* Steve Roberds, PhD  
*Speakers:* Elizabeth Henske, MD; Kimberly Moran, PhD; David Schenkein, MD; Michael Wong, MD, PhD

5:30 to 7 p.m.

Spanish Educational Meeting and Gathering, *Plum Blossom*  
*Facilitator:* Ary Agami  
*Speakers and Event Leader:* Darcy Krueger, MD, PhD; Joao García Martinez, MD

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

- 7 p.m. Texas BBQ Dinner, *The Jade Oval*
- 8:30 p.m. Summer Movie Night on the Lawn, *The Jade Oval*
- 8:30 p.m. Adults with TSC Outing, *Jade Pavilion*
- 8:30 to 11 p.m. Teen Lounge Open, *Fleur de Lis B*

### Saturday, July 28, 2018

- 7 to 8:30 a.m. Breakfast
- 7:30 a.m. to 5:30 p.m. Day Camp, *Atrium 1 – Check-In: Stemmons Ballroom*
- 8 a.m. to 4 p.m. Exhibit Hall and TSC Resource Center, *Grand Ballroom C*
- 8 to 9:30 a.m. **General Session:** Preventative Trials and Cannabidiol (CBD) Treatment for TSC, *Grand Ballroom D/E*  
**Moderator:** Mustafa Sahin, MD, PhD  
**Speakers:** Martina Bebin, MD, MPA; Sergiusz Józwiak, MD, PhD; Chris Kingswood, MBBS, MRCP, FRCP; Shelly Meitzler; Elizabeth Thiele, MD, PhD
- 9:30 to 10 a.m. Break
- 10 to 11:15 a.m. **Fourth Break Out Session**
- Track A: TAND: Autism Spectrum Disorder, Biomarkers, Therapeutic Options and Clinical Trials (for all ages), *Grand Ballroom D/E*  
**Moderator:** Anna Byars, PhD  
**Speakers:** Shafali Jeste, MD; Mustafa Sahin, MD, PhD; Petrus de Vries, MBChB, MRCPsych, PhD
- Track B: Transition into Adulthood: Respite Care and Residential Options, *Grand Ballroom A*  
**Moderator:** Cathy Evanochko  
**Speakers:** Deanna Eble, Esq., Yolande Erickson, JD, Esq.
- Track C: Genetics, Reproductive Issues and Impact on Relationships, *Grand Ballroom B*  
**Moderator:** Luciana A. Haddad, MD, PhD  
**Speakers:** Tamison Jewett, MD; Hope Northrup, MD  
**Panelists:** Seth Fritts; Rob and Shannon Grandia; Matt and Shelly Meitzler; Karina Stormfeldt
- Track D: Preparing Your Family for Epilepsy Surgical Evaluation and Surgery, *Plum Blossom*  
**Moderator:** Michael Frost, MD

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

*Panelists: Patricia Gibson, MSSW, DHL, ACSW; Carol Hoskin, RN; Rob and Lisa Moss; Sean and Lauren Shillinger*

**MEET THE EXPERTS ROUND TABLE Q&A, *Fleur de Lis A***

*Moderator: Linda Lezotte, RN, BSN*

- 11:15 a.m. to 12:30 p.m. TSC Natural History Database Steering Committee Meeting, By invitation only *Presidential Suite*
- 11:15 to 11:30 a.m. BREAK
- 11:30 a.m. to 12:30 p.m. LUNCH and Round Table Discussions:
- Peer-to-Peer Support Volunteer Opportunities, *Grand Ballroom D/E*
    - *Facilitators: Shelly Meitzler, Julie Scroggins*
  - Accessing mTOR Inhibitors and Other TSC Medicines Outside of the U.S., *Fleur de Lis A*
    - *Facilitators: Chris Kingswood, MBBS, MRCP, FRCP; Clare Stuart, MPH*
  - Adults with TSC and Adult Initiative, *Grand Ballroom B*
    - *Facilitators: Rob and Shannon Grandia*
  - Government Action Team, *Plum Blossom*
    - *Facilitators: Sara Chieffo, Debora Moritz, Katie Smith*
  - Parents of/and Transitioning Young Adults, *Fleur de Lis B*
    - *Facilitator: Dena Hook*
  - Step Forward to Cure TSC Walks and Other TS Alliance Special Events (including volunteer opportunities), *Grand Ballroom A*
    - *Facilitators: April Cooper, Gail Saunders*
- 12:30 to 5 p.m. Teen Lounge Open, *Fleur de Lis B*
- 12:30 to 1:45 p.m. **Fifth Break Out Session**
- Track A: Genetics Made Simple, *Grand Ballroom D/E*  
*Moderator: Tamison Jewett, MD*  
*Speakers: Hope Northrup, MD; Julian Sampson, DM, FRCP, FMedSci*
- Track B: \*Transition into Adulthood: Employment and Higher Education, *Grand Ballroom A*  
*Moderator: Dena Hook*  
*Speakers: Jake Irby, Bertha Sanchez Hayden*
- Track C: TAND: Mental Health Issues in Living with TSC as an Adult, *Grand Ballroom B*  
*Moderator: Seth Fritts, MSW*  
*Speaker: Petrus de Vries, MBChB, MRCPsych, PhD*
- Track D: Occupational Therapy, Physical

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

Therapy, and Non-Medical Therapies (Equine, Music, etc.),  
*Plum Blossom*  
*Moderator:* Patricia Gibson, MSSW, DHL, ACSW  
*Panelists:* Reiko Donato, Debora Moritz, Leslie and Chris Russell, Lisa Smiley

GROUP SESSION: \*How to Advocate for You and/or Your Child, Educate Your Healthcare Provider and Appeal Insurance Denials,  
*Fleur de Lis A*

*Moderator:* Ashley Fasciola, RN, BSN

*Panelists:* Jessica Krefting, RN, BSN; Mark Martin; Rob and Lisa Moss; Ashley Pounders, RN, BSN, CCRN; Brooke Simsa

1:45 to 2 p.m.

BREAK

2 to 3:15 p.m.

**Sixth Break Out Session**

Track A: Accessing Early Childhood Services and Navigating the Education System, *Grand Ballroom D/E*

*Moderator:* Carla Fladrowski

*Speakers:* Jennifer Flinn, PhD; Dena Hook

Track B: TAND: Aggressive Behavior Management, *Grand Ballroom A*

*Moderator:* Shafali Jeste, MD

*Speakers:* Anna Byars, PhD; Tanjala Gipson, MD

Track C: \*Navigating the Complexities for Special Needs Care in TSC (Insurance, SSI, Waivers, Medicaid, Access), *Grand Ballroom B*

*Moderator:* Theresa Varnet, MSW, JD

*Speaker:* Yolande Erickson, JD, Esq.

*Panelists:* Rachael Jackson; Tammy Kouns; Julie Rogers, LCSW

Track D: Medical Transition Guidelines for the Neurology Community (Endorsed by AAP, CNS, AES, AAN): Practical Steps and Tools, *Plum Blossom*

*Moderator:* Stephanie Mucha, MPH

*Speaker:* Rebecca Schultz, PhD, RN, CPNP

GROUP SESSION: Building and Sustaining Relationships, *Fleur de Lis A*

*Speaker:* Petrus de Vries, MBChB, MRCPsych, PhD

2 to 3:15 p.m.

Biosample Repository Steering Committee and Advisory Committee, By invitation only, *Presidential Suite*

3:15 to 3:30 p.m.

BREAK

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.

3:30 to 5 p.m.                   **General Session:** Genetics, Biosample, Natural History Data and Potential for Personalized Medicine, *Grand Ballroom D/E*  
*Moderator:* Julian Sampson, DM, FRCP, FMedSci  
*Speakers:* Peter Crino, MD, PhD; Chris Kingswood, MBBS, MRCP, FRCP; Rob Moss; Steve Sparagana, MD

6 p.m.                               Cocktail Meet and Greet in the *Grand Ballroom Foyer*

7 p.m.                               Blue Night Dinner and Tribute to Keith Hall, *Grand Ballroom*  
*Facilitator:* Kari Luther Rosbeck

9 p.m.                               Adults with TSC Outing, *Jade Pavilion*

9 p.m.                               TSC Mom's Outing, *Gossip Bar*  
*Event Leader:* Lauren Shillinger

9 to 11 p.m.                       Teen Lounge Open, *Fleur de Lis B*

### Sunday, July 29, 2014

7 to 8:30 a.m.                      Breakfast, *East Atrium*

7:30 a.m. to Noon                Day Camp, *Atrium 1 – Check-In: Stemmons Ballroom*

### 8:30 to 9:45 a.m.                **Seventh Break Out Session**

Track A: TAND: ADHD and Behavioral Challenges in Children with TSC, *Grand Ballroom D/E*  
*Moderator:* Tanjala Gipson, MD  
*Speakers:* Anna Byars, PhD; Anna Jansen, MD, PhD

Track B: Kidney Issues in Children and Young Adults with TSC, *Grand Ballroom A*  
*Moderator:* John Bissler, MD  
*Speakers:* David Ewalt, MD; Joshua Samuels, MD, MPH

Track C: Organizing Your Thoughts and Emotions (executive functioning), *Grand Ballroom B*  
*Moderator:* Petrus de Vries, MBChB, MRCPsych, PhD  
*Panelists:* TS Alliance Adult Regional Coordinators

Track D: \*Microboards, *Plum Blossom*  
*Moderator:* Dena Hook  
*Speakers:* Cheryl Dinnell

9:45 to 10 a.m.                    BREAK

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.



10 a.m. to 12 p.m.

**General Session:** The Power of Community Advocacy and The  
Inspirational Story of Eric Schmitt, *Grand Ballroom D/E*  
*Moderator:* Mark Vieth  
*Speaker:* Eric Schmitt, JD  
Closing Remarks: Kari L. Rosbeck

TAND stands for TSC Associated Neuropsychiatric Disorders.

\*All are welcome, however, these sessions may be most relevant to individuals living in the United States.