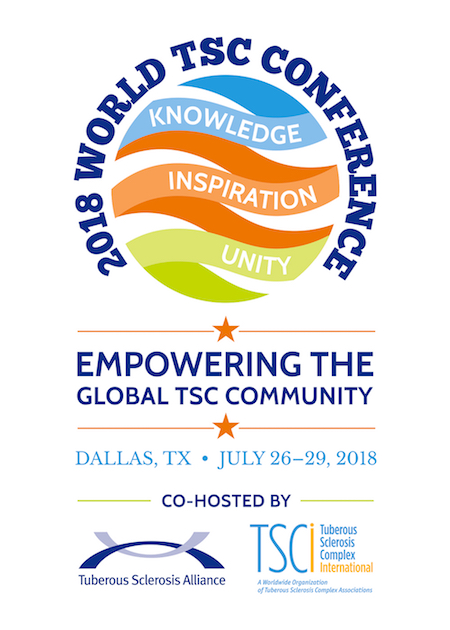
# CONFERENCE AGENDA

*Draft as of October 30, 2017 (All speakers invited and subject to change)*

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# Thursday, July 26, 2018

Noon to 6 p.m. General Conference Registration and Day Camp Registration, *Conference Registration Room and Atrium 2*

10 a.m. to 11:30 a.m.TSC Clinic Directors Meeting\*, *Plum Blossom*

11:30 a.m. to 2:30 p.m. Nurses Meeting\*, *Plum Blossom*

9:00 a.m. – 2 p.m. TSCi Workshop\*, *Fleur de Lis A*

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*
* Grandparents, *Counter Offer*
* Parents of Young Children with TSC (ages 0-13), *Atrium 1*
* Social Networking Groups (Inspire, Facebook), *Plum Blossom*
* Teens and Young Adults (ages 13-25), *Fleur de Lis B*
  + *Facilitators:* Junior Leaders
* Adult Siblings, *Atrium 2*

4:30 to 5:30 p.m. TSC Biosample Repository and TSC Natural History Database Projects Q&A

6 p.m. Conference Welcome and Opening Dinner, *East Atrium*

Welcome from TS Alliance President and CEO Kari Luther Rosbeck, TS Alliance Board Chair Beth Dean, and TSCi Executive Committee Member

8 to 9 p.m. TSC Biosample Repository and TSC Natural History Database Projects Q&A

8:30 pm Social for International Attendees, *Fleur de Lis A*

8:30 p.m. Adults with TSC Evening Activity, *Jade Pavilion*

*Event Leader:* Shannon Grandia

8:30 p.m. TSC Dad’s Outing, *Gossip Bar*

*Event Leader:* Sean Shillinger

8:30 to 11 p.m. Teen Lounge Open, *Fleur de Lis B*

# Friday, July 27, 2018

7 to 8:30 a.m. Breakfast

7:30 a.m. to 5:30 p.m. Day Camp, *Atrium 1 – Check-In: Simmons Ballroom*

8 a.m. to 5 p.m. Exhibit Hall and TSC Resource Center, *Grand Ballroom C*

8:30 to 10 a.m. **Conference Opening Session:** Global Status of TSC and Consensus Guidelines for Diagnosis, Surveillance, and Treatment, *Grand Ballroom D/E*

*Moderator:* Chris Kingswood, MBBS, MRCP, FRCP

*Speakers:* 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. **First Break Out Session**

Track A: Seizure Types and Treatments for Infants and

Children with TSC, *Grand Ballroom D/E*

*Moderator:* James Riviello, Jr., MD

*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*

11:15 a.m. to 12:30 p.m. TSC Natural History Database Steering Committee Meeting\*, *TBD*

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; Robin Shaffert

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

*Moderator:* Joel Moss, MD, PhD

*Speakers:* Elizabeth Henske, MD; FrankMcCormack, MD; Susan Sherman

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:* AriaFallah*,* 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:* Kelly Piacenti, MA; Robin Shaffert; 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

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: Simmons 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 Jóźwiak, MD, PhD; Chris Kingswood, MBBS, MRCP, FRCP; Elizabeth Thiele, MD, PhD

9:30 to 10 a.m. Break

10 to 11:15a.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

*Speaker:* Robin Shaffert

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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

*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 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*
    - *Facilitator:* Shelly Meitzler
  + Advocating for Access to Medicines in Countries with National Payers, *Fleur de Lis A*
    - *Facilitators:* Chris Kingswood, MBBS, MRCP, FRCP; Clare Stuart
  + 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: Non-Medical Therapies: Occupational Therapy, Physical

Therapy, Equine, Music, *Plum Blossom*

*Moderator:* Patricia Gibson, MSSW, DHL, ACSW

*Panelists:* TBD

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:* Amy Brin Miller, MSN, MA, PCNS-BC, ACHPN

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

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

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

3:15 to 3:30 p.m. BREAK

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; David Kwiatkowski, MD, PhD; Steve Sparagana, MD

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

7 p.m. Blue Night Dinner, *Grand Ballroom*

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: Simmons 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

### 10 a.m. to Noon 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

\*By invitation only.  
\*TAND stands for TSC Associated Neuropsychiatric Disorders.