# CONFERENCE AGENDA

*Draft as of July 7, 2017 (All speakers invited and subject to change)*

**

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

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

Welcome from Kari L. Rosbeck, TS Alliance Board of Directors Chair, and TSCi

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*

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; Hope Northrup, MD; Darcy Krueger, MD, PhD

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

Track B: Managing Medical Transitions from Childhood to

 Adulthood, *Grand Ballroom A*

 *Moderator:* Luciana Haddad, MD, PhD

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

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

 *Moderator:* David Ewalt, MD

*Speakers:* Chris Kingswood, MBBS, MRCP, FRCP; John

Bissler, MD; John Hulbert, MD

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; Ray Yeung, MD; Brian Grottkau, MD

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

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; Jonathan Roth, MD; Ian Miller,

MD

Track B: Advocacy in the Education System for Transition into

 Adulthood, *Grand Ballroom A*

 *Moderator:* Dena Hook

 *Speakers:* Robin Shaffert; Jennifer Flinn, EdD

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

 *Moderator:* Joel Moss, MD, PhD

 *Speakers:* George Pappas, MD; Elizabeth Henske, MD; Frank

McCormack, MD

Track D: TAND\*: Sleep Disorders in TSC, *Plum Blossom*

 *Moderator:* Anna Jansen, MD, PhD

 *Speakers:* Jonathan Lipton, MD, PhD; Deborah Briggs, MD; Shafali Jeste, MD

**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:* Howard Weiner, MD, FACS, FAAP; Jonathan Roth,

MD; AriaFallah*,* MD

Track B: Long-Term Care Planning: Special Needs Trusts and Guardianship, *Grand Ballroom A*
*Moderator:* Dena Hook

 *Panelists:* Kelly Piacenti, MA; Theresa Varnet, MSW, JD; Robin Shaffert

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; Michael Wong, MD, PhD; Colin Stott; Kimberly Moran, PhD

5:30 to 7 p.m. Spanish Educational Meeting and Gathering, *Plum Blossom*
*Facilitator:* Ary Agami

*Speakers and Event Leader:* Joao García Martinez, MD; Darcy Krueger, MD, PhD

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:* Elizabeth Thiele, MD, PhD; Sergiusz Jóźwiak, MD, PhD; Martina Bebin, MD, MPA; Chris Kingswood, MBBS, MRCP, FRCP

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:* Mustafa Sahin, MD, PhD; Shafali Jeste, MD;

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

ow

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:* Rob and Shannon Grandia; Matt and Shelly Meitzler; Karina Stormfeldt; Seth Fritts

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

**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:* Christen Bell
	+ Advocating for Access to Medicines in Countries with National Payers, *Fleur de Lis A*
		- *Facilitators:* Clare Stuart; Chris Kingswood, MBBS, MRCP, FRCP
	+ Adults with TSC and Adult Initiative, *Grand Ballroom B*
		- *Facilitators:* Rob and Shannon Grandia
	+ Government Action Team, *Plum Blossom*
		- *Facilitators:* Katie Smith, Debora Moritz, Sara Chieffo
	+ 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:* Lori Denzine, Jake Irby

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; Ashley Pounders, RN, BSN, CCRN; Rob and Lisa Moss; Mark Martin; 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:* Dena Hook; Jennifer Flinn, PhD

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

 *Moderator:* Shafali Jeste, MD

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

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:* Marty Ford

*Panelists*: Tammy Kouns; Rachael Jackson; 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*: David Kwiatowski, MD, PhD; Peter Crino, MD, PhD; Steve Sparagana, MD; Chris Kingswood, MBBS, MRCP, FRCP

6 p.m. Cocktail Meet and Greet in the Grandball Room Foyer

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

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

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 Jansen, MD, PhD; Anna Byars, 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 and the ABLE Act, *Plum Blossom*

*Moderator:* Dena Hook

 *Speakers:* Cheryl Dinnell

9:45 to 10 a.m. BREAK

### 10 a.m. to 12 p.m. General Session: TBA

\*TAND stands for TSC Associated Neuropsychiatric Disorders.