# CONFERENCE AGENDA

**

# Wednesday, July 25, 2018

2 to 6 p.m. TSC Consensus Guidelines Update, By invitation only

# 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 1 p.m. RDCRN PI Meeting, By invitation only, *Presidential Suite*

11:30 a.m. to 2:30 p.m. Empowering Nurse Care Coordination throughout the Global Community, 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

3 to 6 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*: Barry and Sharon Carpenter, Diane McSwain
* 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*
	+ *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, *Cherry Blossom*

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

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

7:30 to 8:30 p.m. TAND Workshop, *Plum Blossom*

7:30 to 9 p.m. Preclinical Consortium Steering Committee, By invitation only, *Presidential Suite*

8 to 9:30 p.m. TSC Biosample Repository and TSC Natural History Database Projects Q&A, *Cherry Blossom*

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, *Atrium I*

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

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

8 to 10 a.m. Conference Registration, *Conference Registration Room and Atrium 2*

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
Welcome:* Kari Luther Rosbeck

*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
Facilitator:* Karen Gilmore

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

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; FrankMcCormack, MD; Susan Sherman, MHA

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:* 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 Leaders:* Darcy Krueger, MD, PhD; Joao García Martinez, MD; Zacil Ha Vilchis Zapata, 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, *Atrium I*

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

8 to 10 a.m. Conference Registration, *Conference Registration Room and Atrium 2*

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; Shelly Meitzler; 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

 *Speakers:* Deanna Eble, Esq., Yolande Erickson, JD, Esq.

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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 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

 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

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: What’s Next? Tools to Empower You on Your Medical Journey to an Adult Neurologist, *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

3:30 to 5 p.m. **General Session**: Genetics, Biosamples, 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, *Atrium I*

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

### 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