

CONFERENCE AGENDA

(All speakers invited and subject to change)

Wednesday, July 25, 2018

2 to 6 p.m.

TSC Consensus Guidelines Update, By invitation only

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

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:* 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*

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- *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>Atrium I</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, <i>Atrium I</i>
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.	Conference Opening Session: 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.	First Break Out Session 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 <i>Speakers:</i> Brenda Porter, MD, PhD; Michal Tzadok, MD; Michael Wong, MD, PhD

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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; Frank McCormack, MD; Susan Sherman, MHA

Track D: TAND: Sleep Disorders in TSC, *Plum Blossom*
Moderator: Anna Jansen, MD, PhD

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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 Leaders: Darcy Krueger, MD, PhD; Joao García Martinez, MD

7 p.m.

Texas BBQ Dinner, *The Jade Oval*

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

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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

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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: 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

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

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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

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