RE-2 Employee Post Travel Disclosure of Travel Expenses

Date/Time Stamp
RECEIVED
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PUBLIC RECORDS
2026 AUG 31 PM 12:08

Post Travel Filing Instructions: Complete this form within **30 days** of returning from travel. Submit all forms to the Office of Public Records in 144 Hart Building. **This form is a public disclosure. The form and attachments will be made publicly available.**

Certification: *In compliance with the Regulations Governing Privately Sponsored Travel, Senate Rule 35, and the Honest Leadership and Open Government Act of 2007, I certify that I accepted the following gift of privately sponsored travel:*

Private Sponsor(s):
TSC Alliance

Travel Dates:
07/31/2026 to 08/02/2026

Name of accompanying family member (if any):

Relationship to Traveler:

Expenses

Transportation Expenses	Lodging Expenses	Meals Expenses	Other Expenses (Amount & Description)
$600.00	$422.00	$230.00	$0.00

I also certify that attached to this form are all required documents for post travel disclosure, including:

- **The final Employee Pre-Travel Authorization** (Form RE-1)
- The final **Private Sponsor Travel Certification Form** with all attachments
- The final invitation
- The final approved itinerary

Finally, I certify that all trip information reflected in the attachments above accurately reflects the travel that I accepted. If there were any changes to the trip after I received approval from the Committee, the changes are described in ATTACHMENT 1.

8/17/2026
Date

MORGAN CORDER
Printed Name of Traveler

Signature of Traveler

TO BE COMPLETED BY SUPERVISING MEMBER/OFFICER

I have made a determination that the expenses set out above in connections with travel described in the Employee Pre-Travel Authorization form, are necessary transportation, lodging, and related expenses as defined in Rule 35.

8/26/26
Date

Signature of Supervising Senator/Officer

ATTACHMENT 1 – CHANGES FROM APPROVED PRE-TRAVEL

Note: Material changes to a trip that occur after the Committee has issued an approval letter may invalidate the Committee's approval. Please contact the Committee with any questions regarding changes to an approved trip.

Were there any changes to the pre-approved travel expenses? (Transportation, Meals, Lodging, Other)?

○ Yes ● No

Expense Change	Revised Amount	Explanation
There were no changes to pre-approved travel expenses.		

Were there any changes to the pre-approved itinerary?

○ Yes ● No

Explanation: There were no changes to the pre-approved itinerary.

Were there any additional changes to the pre-approved trip?

○ Yes ● No

Explanation: There were no additional changes to the pre-approved trip.

Corder, Morgan (Schmitt)

From: Kari Rosbeck <krosbeck@tscalliance.org>
Sent: Friday, June 13, 2025 12:43 PM
To: Corder, Morgan (Schmitt)
Cc: Shelly Meitzler; Katie Smith
Subject: Invitation to the 2026 TSC World Conference
Attachments: Speaker Invite Attachment.pdf



Dear Morgan,

On behalf of the **TSC Alliance** and **Tuberous Sclerosis Complex International (TSCi)**, we are honored to invite you to speak at the **2026 TSC World Conference**, taking place **July 30 – August 1, 2026**, at the **Gaylord Rockies Resort & Convention Center** in Aurora, Colorado. Please note there may be pre-conference workshops and smaller conferences starting earlier in the week.

Our last TSC World Conference in 2022 brought together more than 997 participants from 26 countries, offering unparalleled opportunities for education, collaboration, and community. In 2026, we expect to welcome over 1,000 attendees, including individuals living with TSC, their families and caregivers, and medical professionals. We're confident that next year's event will be even more impactful.

We would be delighted for you to participate in the following sessions:

- **Taking an Active Role in Government Advocacy: State and Federal on** Saturday, August 1 **from** 3:00 PM **to** 4:30 PM **| Role:** Speaker

Your expertise will be invaluable in empowering our community through education and connection. The 2026 conference will include keynote presentations, workshops, interactive discussions, and tailored learning tracks reflecting the full TSC journey.

A draft agenda is attached. We will provide final agenda details and schedule planning calls in early 2026.

Please note: All speakers are asked to sign a release form as sessions will be recorded and made available online at no cost following the event.

To confirm your participation, please reply all to this email or contact **Shelly Meitzler** at smeitzler@tscalliance.org **by October 1, 2025**.

Your voice is a powerful asset in our shared goal to support and bring hope to the global TSC community. We would be truly honored by your participation in this milestone event.

Warm regards,



Kari Luther Rosbeck | President and CEO

TSC Alliance® | Hope no matter how complex™
Main: 301-562-9890 | Mobile: 612-840-7375
tscalliance.org

RE-1 Employee Pre-Travel Authorization

Date/Time Stamp

Pre-Travel Filing Instructions: Complete and submit this form at least 30 days prior to the travel departure date to the **Select Committee on Ethics in SH-220.** Incomplete and late travel submissions will **not** be considered or approved.

Name of Traveler:
MORGAN CORDER

Employing Office/Committee:
SCHMITT, ERIC

Private Sponsor(s):
TSC Alliance

Destination(s):
Aurora, Colorado

Travel Dates:
07/31/2026 to 08/02/2026
NOTE: If you plan to extend the trip for any reason you **must** notify the Committee.

Explain how this trip is specifically connected to the traveler's official or representational duties.

Representing Senator Eric Schmitt and his priorities as it relates to Americans with developmental disabilities.

Do you have an accompanying family member or spouse on this trip?
No

Name and Relationship to Traveler:
N/A

I certify that the information contained in this form is true, complete and correct to the best of my knowledge.

4/13/2026
Date

Signature of Employee

TO BE COMPLETED BY SUPERVISING MEMBER/OFFICER
(President of the Senate, Secretary of the Senate, Sergeant at Arms, Secretary for the Majority, Secretary for the Minority, and Chaplain)

I Office of Sen. Eric Schmitt
(Print Senator's/Officer's Name)

hereby authorize Morgan Corder
(Print Traveler's Name)

an employee under my direct supervision, to accept payment or reimbursement for necessary transportation, lodging, and related expenses for travel to the event described above. I have determined that this travel is in connection with his or her duties as a Senate employee or an officeholder, and will not create the appearance that he or she is using public office for private gain.

I have also determined that the attendance of the employee's spouse or child is appropriate to assist in the representation of the Senate.

☐ (signify "yes" by checking box)

Date

Signature of Supervising Senator/Officer

TSC Alliance: TSC World Conference

MORGAN CORDER

Title:
None

Employing Office/Committee:
SCHMITT, ERIC

Duty Station:
COLUMBIA,MO

Destination(s):

Aurora, Colorado

Explain how this trip is specifically connected to the traveler's official or representational duties:

Representing Senator Eric Schmitt and his priorities as it relates to Americans with developmental disabilities.

Name of accompanying family member (if any):
Not Entered

Name and Relationship to Traveler:
None

Organization Information

Organization Name
TSC Alliance

Is your organization classified as a §501(c)(3)?
(●) Yes ( ) No

§501(c)(3) Organization Type
Public Charity

Address
8737 Colesville Road, Suite 400

Address 2 (Optional)

City, State Zip
Silver Spring, Maryland 20910 United States

Phone Number
(301) 562-9890

Organization URL
tscalliance.org

History of Congressional Travel

None

Educational Activities

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with tuberous sclerosis complex (TSC). TSC is a rare genetic disease that causes tumors to grow in different organs, from the brain and heart to the lungs and kidneys to the skin and eyes. Nearly one million people worldwide have TSC. We are a source of hope and connection for all affected by TSC. We drive research, increase care quality and access and advocate with and for people affected by the disease. Through our collaboration and partnerships, we've advanced FDA-approved treatments and created support systems around the world so that no one has to navigate TSC alone. The TSC community is our strongest ally. With the power of families and the support of donors, volunteers, researchers, educators, industry partners, and more, we can create a future where everyone with TSC can realize their full potential.

Lobbyist and Foreign Agent Registration Information

Lobbyist Registration Status: *I certify that the sponsor is not a federally registered lobbyist but does retain or employ one or more federally registered lobbyists.*

Foreign Agent Registration Status: *I certify that the sponsor is not an agent of a foreign principal and do not retain or employ an agent of a foreign principal.*

Foreign Government Involvement

Foreign Agent Registration Status:

- ☑ I certify that the sponsor is not a foreign government.
- ☑ I certify that the sponsor is not an entity that is owned or operated by a foreign government.
- ☑ I certify that the sponsor does not receive funding from a foreign government.

Comments

Signature Page

The signature page is below.

Purpose and Details

Provide a brief description of the trip.

Staged every four years, the TSC World Conference is the largest and most prolific event the TSC Alliance hosts. Conference Attendees will receive: The latest and most comprehensive TSC diagnosis, treatment and research information from the leading TSC clinicians and scientists Assistance through the myriad of educational, financial, and emotional challenges of TSC The opportunity to meet hundreds of other families and individuals with TSC and make life-long connections A better understanding of the role the TSC Alliance plays in research, support and government advocacy in the United States Access to a wide range of service providers Multiple networking opportunities Q&A sessions with the experts at the end of Friday and Saturday's sessions

Explain how the purpose of the trip relates to your organization's mission.

The TSC Alliance mission statement is to include quality of life for everyone affected by TSC by catalyzing new treatments, driving research toward a cure, and expanding access to lifelong support. The TSC World Conference sessions address all aspects of our mission statement and by educating the TSC community they can make informed decisions that improve quality of life.

Is your organization the only sponsor for this trip?

- [x] Yes
- [ ] No

Grantmaking Organizations (Optional)

There are no grantmaking organizations.

With or Without Regard for Congressional Participation

The trip is arranged or organized without regard to congressional participation.

Lobbyist/Foreign Agent Involvement in Planning, Organizing, Requesting or Arranging

- [x] The trip will not in any part be planned, organized, requested, or arranged by a registered lobbyist or agent of a foreign principal, other than de minimis involvement.

Lobbyist/Foreign Agent Financing

- [x] The trip will not be financed in any part by a registered lobbyist or agent of a foreign principal.
- [x] No funds or in-kind contributions were earmarked directly or indirectly for the purpose of financing this specific trip from a registered lobbyist or agent of a foreign principal or from a private entity that retains or employs one or more registered lobbyists or agents of a foreign principal.

Lobbyist/Foreign Agent Accompaniment

Complete if all sponsors are §501(c)(3) organizations

- [x] The trip is limited to three days (for trips inside the continental United States) or seven days (for trips outside the continental United States), and no lobbyist or agents of a foreign principal will accompany the Member, officer, or employee at any point throughout the trip
- [ ] The trip is limited to a one-day event (exclusive of travel time and **one** overnight stay) and no registered lobbyists or agents of a foreign principal will accompany the Member, officer, or employee on any segment of the trip
- [ ] The trip is limited to a one-day event (exclusive of travel time and **two** overnight stays) and no registered lobbyists or agents of a foreign principal will accompany the Member, officer, or employee on any segment of the trip

Complete if any of the sponsors is not a §501(c)(3) organizations.

- [ ] The trip is limited to three days (for trips inside the continental United States) or seven days (for trips outside the continental United States), and no lobbyist or agents of a foreign principal will accompany the Member, officer, or employee at any point throughout the trip
- [ ] The trip is limited to a one-day event (exclusive of travel time and **one** overnight stay) and no registered lobbyists or agents of a foreign principal will accompany the Member, officer, or employee on any segment of the trip
- [ ] The trip is limited to a one-day event (exclusive of travel time and **two** overnight stays) and no registered lobbyists or agents of a foreign principal will accompany the Member, officer, or employee on any segment of the trip

Certification of No Recreational Activity and No Alcohol

- ✓ Travel expenses paid for will not include expenditures for recreational activities.
- ✓ Travel expenses paid for will not include expenditures for alcohol, except as permitted by the Regulations Governing Privately Sponsored Travel.

Invitees

ⓘ Members and staff from the House of Representatives **will not** receive invitations.

The list of invitees is below.

Travel Details

Trip Start Date/Time:
07/31/2026 @ 08:00 AM

Trip End Date/Time:
08/02/2026 @ 05:00 PM

Will the traveler be accompanied by a family member for whom the sponsor will pay travel expenses?

○ Yes ● No

Itinerary

The itinerary is below.

Transportation (Per Member/Officer/Employee: $600.00 | Accompanying Family Member: $0.00)

Transportation Type	Class	Amount
Airfare	Coach	$500.00
Note Roundtrip flight to Aurora, CO		
Ground Transportation	N/A	$100.00
Note ground transportation to and from the airport		

Lodging (Per Member/Officer/Employee: $422.00)

Check-In	Check-Out	Facility	City	State	Country	Nights	Cost/Night	Cost Exceed Per Diem
07/31/2026	08/02/2026	Gaylord Rockies	Aurora	Colorado	United States	2	$211.00	No

Meals (Per Member/Officer/Employee: $230.00)

Date	Breakfast	Lunch	Dinner	Incidentals	Total	City	State	Country	Cost Exceeds Per Diem
07/31/2026	$0.00	$50.00	$0.00	$0.00	**$50.00**	Denver	Colorado	United States	No
08/01/2026	$40.00	$50.00	$90.00	$0.00	**$180.00**	Aurora	Colorado	United States	Yes

Cost Exceeds Per Diem Reason
Preset conference meals at a pre-negotiated rate with the hotel.

Reasonable Miscellaneous Expenses (Per Member/Officer/Employee: $0.00)

Expense Type	Amount	Notes
There are no miscellaneous expenses.		

Additional Attachments All additional attachments are below.

Document Name

Conference Agenda

2026 TSC World Conference Agenda Corder

2026 TSC World Conference Agenda Corder

PRIVATELY SPONSORED TRAVEL

SPONSOR SIGNATURE PAGE

I hereby certify that the information submitted in connection with the trip listed below is true, complete, and correct to the best of my knowledge and belief.

Trip Name: TSC World Conference

Travel Date(s): July 31-August 2

Travel Destination(s): Aurora, Colorado

Sponsor: TSC Alliance

Kari Luther Rosbeck — *(printed name of sponsor representative)*

President and CEO — *(title)*

Kari Luther Rosbeck — *(signature of sponsor representative)*

4/10/26 — *(date)*

2026 TSC World Conference Invited Speakers

Ary Agami, TSC Alliance of Mexico
Dean Aguiar, PhD, TSC Alliance
Sam Amin, MBCHB, MRCPCH, MSc, PhD, University Hospitals Bristol
Gil Amit, TSC Alliance Israel
Lilian Ansari
Derek Bauer, MD, University of Rochester
Clayton Beard, PhD , Bridgebio
E. Martina Bebin, MD, MPA, University of Alabama, Birmingham
Allyson Berent, DVM, DACVIM, FAST
Anita Bhatia, MHA , Ramesh and Kalpana Bhatia Family Foundation
Wynne Bird, BSN, RN, CPN, Children's Hospital Colorado
Stacey Bissell, PhD, University of Bristol
John Bissler, MD, Le Bonheur Children's Hospital
Jeffrey Blount, MD, MPH, University of Alabama, Birmingham
Jeffrey Calhoun, PhD, Northwestern University
Jamie Capal, MD, Cincinnati Children's Hospital Medical Center
Liz Cassidy, MPH, TSC Alliance
Sara Chieffo
Asim Choudhri, MD, Le Bonheur Children's Hospital
Danielle Clark, MPH, MS, RD, LD
Rohini Coorg, MD, Texas Children's Hospital
Morgan Corder, United States Senator Eric Schmitt
Margaret Cox
Peter Crino, MD, PhD, University of Maryland School of Medicine
Kate Crossett
Kristn Currans, PsyD, Cincinnati Children's Hospital Medical Center
Daniel Curry, MD, Texas Children's Hospital
Thomas Darling , MD, PhD, Uniformed Services University of the Health Sciences
Peter Davis, MD, Boston Children's Hospital
Mary Duffy, Danny Did Foundation
Petrus de Vries, MBChB, FRCPsych, PhD, University of Capetown
Allison Divanovic , MD, Cincinnati Children's Hospital Medical Center
Emily Docktor, LMSW, New Hope Therapeutic Services
Reiko Donato
Greg Downey, MD, FRCPC, National Jewish Health
Deanna Eble, Esq., Russo Law Group
Kevin Ess, MD, PhD, Children's Hospital Colorado
Aria Fallah, MD, MS, Unversity of California Los Angeles
Laura Farach, MD, University of Texas Health Science Center at Houston
Richard Faris, PhD, PANTHERx Rare Pharmacy
Jennifer Flinn, EdD, TS Canada ST
Rod Foroozan, MD, Baylor University
Thomas Foutz, MD, PhD, Washington University
Cori Fratelli, MSN, FNP-C, RN, National Jewish Health
Lara Friel, MD, PhD, University of Texas Health Science Center at Houston
Pradnya Gadgil, MBBS, MRCPCH, SRCC Children's Hospital by NH
Joao García Martínez, MD, Clínica Neural
Tanjala Gipson, MD, Le Bonheur Children's Hospital
Jennifer Glass, LGC, Cincinnati Children's Hospital Medical Center

Jonathan Goldstein
Lainey Goodwill, JD, University of Memphis School of Law's Medical-Legal Partnership Clinic
Elizabeth Gosnell, DMD, MS, Cincinnati Children's Hospital Medical Center
Rob Grandia
Shannon Grandia
Bailey Green
Nishant Gupta, MD, University of Cincinnati
Lyndsay Harshman, MD, MS, University of Iowa
Elizabeth (Lisa) Henske, MD, Brigham and Women's Hospital
Mark Hester, PhD, Nationwide Children's Hospital
Kim Hindery, Child Neurology Foundation
Billy Holcombe, PhD, Children's Healthcare of Atlanta
Lesley Holmes, JD
Allison Hulme, PhD, Aeovian Pharmaceuticals
Emilie Hyde
S. Katie Ihnen, MD, PhD, Cincinnati Children's Hospital Medical Center
Anna Jansen, MD, PhD, University of Antwerp
Shafali Jeste, MD, Children's Hospital Los Angeles
Simon Johnson , DM, FCRP, University of Nottingham
Monika Jones, JD, CNP, Pediatric Epilepsy Surgery Alliance
Sergiusz Jóźwiak, MD, PhD, Medical University of Warsaw
Mark Keezer, MDCM, PhD, Centre Hospitalier de l'Université de Montréal
Chris Kingswood, MD, St. Georges and Sussex University Hospitals
Jessica Krefting, BSN, RN, University of Alabama, Birmingham
Darcy Krueger, MD, PhD, Cincinnati Children's Hospital Medical Center
Bernice Martin Lee, Epilepsy Foundation
Jonathan Lipton, MD, PhD, Boston Children's Hopsital
Andy Liu, MD, Duke University
Joanna Lomas-Mevers, PhD, BCBA-D, Marcus Autism Center
Stig Magne Evju Brekken, TSC Norway
Julian Martinez-Agosto, MD, PhD, FACMG, University of California, Los Angeles
Jennifer McCrave, BSN, RN, CNRN, Boston Children's
Mary McDirmid, ChSNC, ChFC, All Needs Planning
Nicole McDonald, PhD, University of California, Los Angeles
Shelly Meitzler, TSC Alliance
Lisa Moore-Ramdin, MBBS, MRCPCH, DPM, FFPM, Jazz Pharmaceuticals
Joel Moss, MD, PhD, National Heart, Lung, and Blood Institute
Rob Moss, Seizure Tracker
Iris Mustich, MPH
Fábio Nascimento, MD, Washington University School of Medicine
Danielle Nolan, MD, Corewell Health East/Beaumont TSC Clinic
Hope Northrup, MD, University of Texas Health Science Center at Houston
Guinevere Pandolfi
Elahna Paul, MD, PhD, Massachusetts General Hospital
Angela Peron, MD, PhD, Università degli Studi di Firenze
Donald Phillips, MD, MPH, FACNS, Children's Hospital of Orange County
Brenda Porter, MD, PhD, Stanford University
Gwen Pryor
~~Heather Radtke, MS, CGC, TSC Alliance~~

Raj Rajaraman, MD, MS, University of California, Los Angeles
Stephanie Randle, MD, MS, Seattle Children's Hospital
Kate Richardson, MS, CGC, University of Texas Health Science Center at Houston
David Ritter, MD, PhD, Cincinnati Children's Hospital and Medical Center
Steven L. Roberds, PhD, TSC Alliance
David Rodriguez-Buritica, MD, University of Texas Health Science Center at Houston
Kari Luther Rosbeck, TSC Alliance
Jonathan Roth , MD, Tel Aviv Sourasky Medical Center
Mustafa Sahin, MD, PhD, Boston Children's Hospital
Jay Salpekar, MD, FANPA, Kennedy Krieger Institute
Alice Bryn Salter, MD, Duke University
Joshua Samuels, MD, MPH, University of Texas Health Science Center at Houston
Claire Sartwell, RN, BSN, University of Texas Health Science Center at Houston
Liezl Schlebusch, PhD, University of Capetown
Irfan Sheikh, MD, UT Southwestern Medical Center
Lauren Shillinger
Sean Shillinger
Elizabeth Skufca, TSC Alliance
Brittany Smith, Chair, TSC Alliance Board of Directors
Katie Smith, TSC Alliance
Lisa Szilagyi, University of Utah
Pooja Takhar, PhD , Tuberous Sclerosis Association
Priya Tatachar, MD
Joyce Teng, MD, PhD, Standford University
Elizabeth Thiele, MD, PhD, Massachusettes General Hosptial
Tammy Thorne, Social Security Administration
Abby Turnwald, MS, CGC
Agnies van Eeghen, MD, PhD, Amsterdam UMC
Mark Vieth, CRD Associates
Zacil Vilchis, MD, MSc, Universidad Anáhuac Mayab
Vijay Vishwanath, MD, PhD, Children's Hospital Los Angeles
Oded Volovelsky, MD, PhD, The Hebrew University of Jerusalem
Deanna Wall, MHA, University of Utah
Sarah Weatherspoon, MD, Le Bonheur Children's Hospital
Laura Weidner, JD, Epilepsy Foundation
James Wheless, MD, Le Bonheur Children's Hospital
Michael Wong, MD, PhD, WashU Medicine
Wenbo Zhang, MD, Minnesota Epilpesy Group

For more information, please contact
Lisa Moss, lmoss@tscalliance.org
Ryan Beebe, rbeebe@tscalliance.org



Conference Agenda

Draft as of February 7, 2026. All speakers invited and subject to change.

Pre-Conference Webinars

TSC 101 for Newly Diagnosed Individuals or Families – April 29 at 8 PM ET

- Jennifer McCrave, BSN, RN, CNRN (moderator); Raj Rajaraman, MD, MS; Elizabeth Thiele, MD, PhD

Consensus Guidelines: What You Need to Know – May 11 at 1 PM ET

- Chris Kingswood, MD (moderator); Darcy Krueger, MD, PhD; Hope Northrup, MD

Seizure Types in TSC – June 3 at 12 PM ET

- Shelly Meitzler (moderator); Sam Amin, MBCHB, MRCPCH, MSc, PhD; E. Martina Bebin, MD, MPA

Genetics Made Simple – June 17 at 8 PM ET

- Danielle Nolan, MD (moderator); Hope Northrup, MD

mTOR Inhibitors: Past, Present and Future – June 30 at 8 PM ET

- Elizabeth Skufca (moderator); David Ritter, MD, PhD; Michael Wong, MD, PhD

Wednesday, July 29, 2026

Consensus Guidelines Sessions (Invite Only)
TSCi Meeting (Invite Only)
TSCi and Consensus Dinner (Invite Only)

Thursday, July 30, 2026

Consensus Guidelines Sessions (Invite Only)
TSCi Meeting (Invite Only)
12:30 PM - 5:45 PM Day Camp Open
12:00 PM - 5:00 PM Exhibit Hall Open
1:00 PM - 2:30 PM The State of TSC Around the World
Opening Keynote

- Kari Luther Rosbeck (welcome); Pradnya Gadgil, MBBS, MRCPCH (moderator); Kevin Ess, MD, PhD; Jennifer Flinn, EdD (community speaker); Anna Jansen, MD, PhD

2:45 PM - 4:15 PM Seizure Treatments
Breakout Sessions 1

- Priya Tatachar, MD (moderator); Sam Amin, MBCHB, MRCPCH, MSc, PhD; Peter Crino, MD, PhD; Rod Foroozan, MD; Thomas Foutz, MD, PhD; Darcy Krueger, MD, PhD

Thursday, July 30, 2026 continued

2:45 PM - 4:15 PM
Breakout Sessions 1

Federal Assistance Programs and Special Needs Trusts
- Tammy Thorne (moderator), Mary McDirmid, ChSNC, ChFC; Deanna Eble, Esq.; Lainey Goodwill, JD

TSC 101 for Ages 8-17
- Stig Magne Evju Brekken (moderator); Guinevere Pandolfi (community speaker); Emily Docktor, LMSW, Jennifer Glass, LGC

Treatment Options and Clinical Trials in LAM
- Joel Moss, MD, PhD (moderator); Gwen Pryor (community speaker); Greg Downey, MD, FRCPC; Elizabeth (Lisa) Henske, MD; Simon Johnson, DM, FCRP

Sexual Development for Dependent and Semi-Independent TSC Adults
- Fábio Nascimento, MD (moderator); Agnies van Eeghen, MD, PhD

Health Issues for Men with TSC
- Jonathan Goldstein (moderator), Derek Bauer, MD; Mark Keezer, MDCM, PhD; Joshua Samuels, MD, MPH

4:30 PM - 6:00 PM

Meet and Greets
- Adults with TSC (ages 28+)
- Young Adults with TSC (ages 17-27)
- Teens and Young Adults with TSC (ages 13-16)
- Parents of Dependent and Semi-Independent Adults with TSC
- Parents of Independent Adults with TSC
- Parents/Caregivers of Transition-Age Young Adults
- Parents of Young Children with TSC (ages 0-13)
- Grandparents
- Adult Siblings

Reunión Para Familias Hispanohablantes hosted by TSC Alliance of Mexico

Clinic Directors and Clinic Staff Meeting
- By invitation only

6:30 PM - 8:30 PM

Opening Dinner
- Kari Luther Rosbeck (Emcee); Kevin Ess, MD, PhD; Brittany Smith, Chair, TSC Alliance Board of Directors; Pooja Takhar, PhD

8:30 PM

Informal Evening Socials
- Adults with TSC, Teen Lounge, International Attendees, Dad's Night, Dependent Adults and Caregivers

Friday, July 31, 2026

7:00 AM - 8:30 AM Breakfast
7:30 AM - 5:45 PM Day Camp Open
8:00 AM - 5:00 PM Exhibit Hall Open

8:30 AM - 10:00 AM Keynote Address

TSC Community-Driven Research and Global TAND Collaborations

- Steven L. Roberds, PhD; (moderator), Anita Bhatia, MHA (community speaker); Dean Aguiar, PhD; Liz Cassidy, MPH; Petrus de Vries, MBChB, FRCPsych, PhD; Agnies van Eeghan, MD, PhD

8:30 AM - 12:00 PM

Sibling Workshop (ages 7-12)

- Shelly Meitzler (moderator); Abby Turnwald, MS, CGC

10:00 AM - 10:30 AM Break

10:30 AM - 12:00 PM Breakout Sessions 2

Dysregulated Behaviors

- Tanjala Gipson, MD (moderator); Jamie Capal, MD; Peter Davis, MD; Lauren and Sean Shillinger (community speakers)

Reproductive Decision Making and Childbearing Considerations

- Heather Radtke, MS, CGC (moderator), Iris Mustich, MPH (community speaker), Lara Friel, MD, PhD; Jennifer Glass, LGC; Lyndsay Harshman, MD, MS

Accessing Early Childhood Services and Non-Medical Therapies

- Shelly Meitzler (moderator); Joanna Lomas-Mevers, PhD, BCBA-D; Claire Sartwell, BSN, RN

SEGA Management Over the Lifespan

- Brenda Porter, MD, PhD (moderator), Elizabeth Thiele, MD, PhD; Daniel Curry, MD; Asim Choudhri, MD; Pradnya Gadgil, MBBS, MRCPCH

Transition into Adulthood for Semi-Independent and Dependent Adults: Living Centers and Employment Options

- Mary McDirmid, ChSNC, ChFC (moderator); Lisa Szilagyi; Deanna Wall, MHA

Organizing Your Thoughts and Emotions and Managing Relationships (only open to adults with TSC)

- Shannon and Rob Grandia (moderators and community speakers), Danielle Clark, MPH, MS, RD, LD (community speaker); Petrus de Vries, MBChB, FRCPsych, PhD

12:00 PM - 1:00 PM Lunch

12:00 PM - 5:00 PM Teen Lounge Open

1:00 PM -2:30 PM Breakout Sessions 3

Kidney Tumors, Cysts and Treatment Options

- Chris Kingswood, MD (moderator); Lyndsay Harshman, MD, MS; Elahna Paul, MD, PhD; Joshua Samuels, MD, MPH; Oded Volovelsky, MD, PhD

Mood, Anxiety and Overactive/Impulsive Behaviors

- *Anna Jansen, MD, PhD (moderator); Jamie Capal, MD;* Alice Bryn Salter, MD; Agnies van Eeghen, MD, PhD

Seizure Action Plans and Rescue Medications

- Vijay Vishwanath, MD, PhD (moderator); Rob Moss; Raj Rajaraman, MD, MS; Irfan Sheikh, MD

Friday, July 31, 2026 continued

1:00 PM -2:30 PM **Fetal and Perinatal Health**

- Heather Radtke, MS, CGC (moderator); Allison Divanovic, MD; Stephanie Randle, MD, MS; David Ritter, MD, PhD; Sarah Weatherspoon, MD

Pre-Puberty and TAND

- Mustafa Sahin, MD, PhD (moderator); Peter Davis, MD; Shafali Jeste, MD; Joanna Lomas-Mevers, PhD, BCBA-D

Preparing Your Family for Epilepsy Surgical Evaluation and Surgery

- Brenda Porter, MD, PhD (moderator); Lesley Holmes, JD (community speaker); Emilie Hyde (community speaker); S. Katie Ihnen, MD, PhD; Monika Jones, JD, CNP

Sibling Panel Discussion (ages 13+)

- Abby Turnwald, MS, CGC

2:30 PM - 3:00 PM **Break**

3:00 PM - 4:30 PM Breakout Sessions 4 **Epilepsy Surgery and Brain Imaging**

- Stephanie Randle, MD, MS (moderator); Jeffrey Blount, MD, MPH; Aria Fallah, MD, MS; Jonathan Roth, MD; Wenbo Zhang, MD

Autism: Diagnosis, Therapy and Managing Behaviors

- Peter Davis, MD, (moderator); Petrus de Vries MBChB, FRCPsych, PhD; Shafali Jeste, MD; Nicole McDonald, PhD, MS; Mustafa Sahin, MD, PhD

Advocacy and Navigating the Education System (Children and Transition-Age)

- Elizabeth Skufca (moderator); Jennifer Flinn, EdD; Lainey Goodwill, JD; Billy Holcombe, PhD; Shelly Meitzler

Managing Progressive Kidney Disease

- John Bissler, MD (moderator); Elahna Paul, MD, PhD; Joshua Samuels, MD, MPH

Living with LAM

- Elizabeth (Lisa) Henske, MD (moderator); Cori Fratelli, MSN, FNP-C, RN; Nishant Gupta, MD; Joel Moss, MD, PhD

Navigating Issues Living with TSC as an Independent Adult (TAND, Epilepsy, Surveillance)

- Derek Bauer, MD (moderator); Jamie Capal, MD; David Ritter, MD, PhD

4:30 PM - 4:45 PM **Break**

4:45 PM - 5:30 PM **End of Day Q&A**

- Shafali Jeste, MD (moderator); John Bissler, MD; Jamie Capal, MD; Daniel Curry, MD; Nishant Gupta, MD; Anna Jansen, MD, PhD; Brenda Porter, MD, PhD; David Ritter, MD, PhD

6:00 PM - 8:00 PM **Reunión y Cena Para Familias Hispanohablantes**

- *Ary Agami (moderator); Joao García Martínez, MD; Darcy Krueger, MD, PhD; Zacil Vilchis, MD, MSc*

8:30 PM **Informal Evening Socials**

- Movie (TBD)
- Teen Lounge
- Adults with TSC
- Dependent Adults and Caregivers

Saturday, August 1, 2026

7:00 AM - 8:30 AM Breakfast
7:30 AM - 5:45 PM Camp Open
8:00 AM - 5:00 PM Exhibit Hall Open

8:30 AM - 10:00 AM **Empowering the TSC Community: Research, Treatment, and What Comes Next**

- Raj Rajaraman, MD, MS (moderator); Bailey Green (community speaker); Lisa Moore-Ramdin, MBBS, MRCPCH, DPM, FFPM; Elizabeth Thiele, MD, PhD
- Panel: E. Martina Bebin, MD, MPA; Sergiusz Jóźwiak, MD, PhD; and Darcy Krueger, MD, PhD

10:00 AM - 10:30 AM Break

10:30 AM - 12:00 PM
Breakout Sessions 5

Future Role of Genetics in Personalized Medicine

- Hope Northrup, MD (moderator); Jeffrey Calhoun, PhD; Laura Farach, MD; Angela Peron, MD, PhD

Being Proactive with Lifelong Health: Aging and Effects on Brain Health

- Thomas Foutz, MD, PhD (moderator); Peter Crino, MD, PhD; Andy Liu, MD; Irfan Sheikh, MD

Behavioral Plans

- Kim Hindery (moderator); Kristn Currans, PsyD; Billy Holcombe, PhD; Joanna Lomas-Mevers, PhD, BCBA-D

Other Organ Involvement Through the Lifespan: Heart, Eyes, Liver and Pancreas

- Kate Richardson, MS, CGC (moderator); Rod Foroozan, MD; David Ritter, MD, PhD; David Rodriguez-Buritica, MD

Sleep

- Zacil Vilchis, MD, MSc (moderator); Stacey Bissell, PhD; Jonathan Lipton, MD, PhD; Donald Phillips, MD, MPH, FACNS

Caregiver Resources: Self and Respite Care

- Chris Kingswood, MD (moderator); Gil Amit; Lilian Ansari; Liezl Schlebusch, PhD

12:00 PM - 1:00 PM Lunch
12:00 PM - 5:00 PM Teen Lounge Open

1:00 PM - 2:30 PM
Breakout Sessions 6

Genetic Therapies: Hope and Hurdles

- Elizabeth Thiele, MD, PhD (moderator); Allyson Berent, DVM, Dpl. ACVIM; Clayton Beard, PhD; Mark Hester, PhD; Julian Martinez-Agosto, MD, PhD, FACMG

SUDEP Risk and Seizure Monitoring Technology

- James Wheless, MD (moderator); Peter Crino, MD, PhD; Mary Duffy; Bernice Martin Lee; Donald Phillips, MD, MPH, FACNS

Saturday, August 1, 2026 continued

1:00 PM - 2:30 PM
Breakout Sessions 6

Caregiver Wellbeing
- Katie Smith (moderator); Anna Jansen, MD, PhD; Liezl Schlebusch, PhD

Navigating Insurance and Specialty Pharmacy
- Wynne Bird, BSN, RN, CPN (moderator); Richard Faris, PhD; Jessica Krefting, BSN, RN; Claire Sartwell, BSN, RN

Health Issues for Women with TSC
- Elizabeth (Lisa) Henske, MD (moderator); Lara Friel, MD, PhD; Mark Keezer, MDCM, PhD; Kate Richardson, MS, CGC

Navigating the Education System for a High School Certificate
- Jennifer Flinn, EdD (moderator); Lilian Ansari; Kate Crossett; Elizabeth Skufca

2:30 PM - 3:00 PM Break

3:00 PM - 4:30 PM
Breakout Sessions 7

Taking an Active Role in Government Advocacy: State and Federal
- Sara Chieffo (moderator); Allison Hulme, PhD; Mark Vieth; Laura Weidner, JD;
- State Funding Panel: Morgan Corder; Margaret Cox; Peter Crino, MD, PhD

Overview of TAND Medications for Harmful and Disruptive Behaviors
- Mustafa Sahin, MD, PhD (moderator); Jay Salpekar, MD, FANPA

Transition into Adulthood for Independent Adults: Preparing for Employment and Higher Education
- Jonathan Goldstein (moderator); Derek Bauer, MD; Iris Mustich, MPH; Guinevere Pandolfi

Refractory Seizure Management and Tools
- Rohini Coorg, MD (moderator); Sam Amin, MBCHB, MRCPCH, MSc, PhD; Rob Moss; Irfan Sheikh, MD; James Wheless, MD

Skin and Dental Manifestations and Treatment Options
- Thomas Darling, MD, PhD (moderator); Elizabeth Gosnell, DMD, MS; Joyce Teng, MD, PhD

Medical and School Records, Organizing Documents, EMR
- Wynne Bird, BSN, RN, CPN (moderator); Liz Cassidy, MPH; Reiko Donato

4:45 PM - 5:45 PM

End of Day Q&A and Closing Remarks
- Steven L. Roberds, PhD (moderator and closing remarks); Peter Crino, MD, PhD; Thomas Darling, MD, PhD; Petrus de Vries, MBChB, FRCPsych, PhD; Elizabeth (Lisa) Henske, MD; Mark Hester, PhD; Mustafa Sahin, MD, PhD; Angela Peron, MD, PhD; Elizabeth Thiele, MD, PhD

6:30 PM - 8:30 PM

Blue Night: Closing Dinner Followed by DJ and Dancing
- Kari Luther Rosbeck (emcee)

8:30 PM

Evening Socials
- *Teen Lounge*
- Adults with TSC
- Mom's Night
- Dependent Adults and Caregivers

Conference Session Content

Session Types

Keynote/General Sessions (recorded) will feature 3-4 speakers with a moderator and include formal presentations on topics that impact individuals across the lifespan with some time at the end for Q&A.

Panel Presentations (recorded) will feature 3-4 speakers with a moderator who will ask questions to engage interactive conversation amongst the panel and the attendees.

Workshops (non-recorded) are interactive working groups featuring 3-4 speakers, a moderator, and a key take-away learning objective with supporting materials.

Specialty Topic Lectures (recorded) will feature 2+ speakers with a moderator to focus on specialty topics that affect the TSC community.

Discussion Groups (non-recorded) will feature 2-3 speakers and a moderator to discuss more personal topics that affect the TSC community in a closed setting.

End of Day Q&A Sessions, Adams A
The 2026 TSC World Conference includes two end-of-day Question and Answer Sessions. These sessions feature TSC experts who are available for general discussion and questions on any topics related to TSC.

- Friday, July 31: 4:45 to 5:30 p.m.
  Moderator: Shafali Jeste, MD
  Panelists: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

- Saturday, August 1: 4:45 to 5:30 p.m.
  Moderator: Steve Roberds, PhD
  Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD



2026 TSC WORLD CONFERENCE

Agenda and Session Descriptions

Wednesday
July 29, 2026

12:00 p.m. - 6:00 p.m. Conference Registration, *Cottonwood Foyer*

Thursday
July 30, 2026

7:00 a.m. - 3:00 p.m. Biosample Repository Blood Draw Available, *Spruce 1*

8:00 a.m. - 6:00 p.m. Conference Registration, *Cottonwood Foyer*

12:00 p.m. - 5:00 p.m. Exhibit Hall, *Adams Pre-function*
Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
Research Room, *Spruce 1*

1:00 p.m. - 2:30 p.m. OPENING KEYNOTE: The State of TSC Around the World, *Adams A*
Moderator: Pradnya Gadgil, MBBS, MRCPCH
Community Speaker: Jennifer Flinn, EdD
Speakers: Kevin Ess, MD, PhD, Anna Jansen, MD, PhD, Kari Luther Rosbeck
Sponsored by: Filana Therapeutics, Inc.

Kick off the conference with an inspiring keynote that takes you on a journey across continents, offering a dynamic, big-picture view of tuberous sclerosis complex (TSC) research and care worldwide.

2:30 p.m. - 2:45 p.m. BREAK

2:45 p.m. - 4:15 p.m. FIRST BREAKOUT SESSION

Seizure Treatments, *Adams A*
Moderator: Priya Tatachar, MD
Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Peter Crino, MD, PhD, Rod Foroozan, MD, Thomas Foutz, MD, PhD, Darcy Krueger, MD, PhD
Sponsored by: Filana Therapeutics, Inc., LivaNova, and Montara Therapeutics

This session will address seizure treatments available across all ages, as well as discussion about updated guidelines for the use of vigabatrin.



Federal Assistance Programs and Special Needs Trusts, *Maple 3*
Moderator: Tammy Thorne
Speakers: Deanna Eble, Esq., Lainey Goodwill, JD, Mary McDirmid, ChSNC, ChFC
Sponsored by: MassMutual Special*Care*

This panel session will discuss the transition from childhood to adulthood and the services and supports needed for dependent adults, including their future financial and daily living needs and the timelines and common issues around these processes. The session includes perspectives from US based financial and legal experts, as well as TSC community members.

TSC 101 for Ages 8-17, *Spruce 3-4*
Moderator: Mikenna McFadden
Speakers: Emily Docktor, LMSW, Jennifer Glass, LGC
Sponsored by: Chemistry Rx

Through age-appropriate discussion and interactive activities, this workshop will help children and teens living with TSC and their siblings understand what TSC is and learn how it affects the body, brain, and daily life.

Treatment Options and Clinical Trials in LAM, *Maple 4*
Moderator: Joel Moss, MD, PhD
Community Speaker: Gwen Pryor
Speakers: Greg Downey, MD, FRCPC, Elizabeth (Lisa) Henske, MD, Simon Johnson, DM, FCRP
Sponsored by: Praxis Precision Medicines

This session addresses the link between TSC and lymphangioleiomyomatosis (LAM). Learn about treatment options, available clinical trials, and resources and support available for those with LAM.

Sexual Development for Dependent and Semi-Independent TSC Adults, *Maple 5*
Moderator: Fábio Nascimento, MD
Speakers: Agnies van Eeghen, MD, PhD

This session will explore the important but often overlooked topic of sexual development in individuals with TSC who are dependent or semi-independent. As individuals with TSC move into adolescence and adulthood, they experience the same physical and emotional changes as their peers but may face unique challenges when it comes to communication, boundaries, education, and safety.

Men's Health Issues for Adults with TSC, *Spruce 2*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Mark Keezer, MDCM, PhD, Joshua Samuels, MD, MPH

As men with TSC move through adulthood, they may face specific health concerns that are often overlooked. This session focuses on the unique medical, neurological, and psychosocial aspects of living with TSC as an adult male.

4:15 p.m. – 4:30 p.m. BREAK

2026 TSC WORLD CONFERENCE

Thursday (cont.)

4:30 p.m. - 6:00 p.m. MEET AND GREET OPPORTUNITIES

Adults with TSC (ages 28+), *Spruce 2*
Hosted by: Kate Crossett and Seth Fritts
This casual, peer-focused gathering is an opportunity for adults with TSC (age 28 and up) to connect, share experiences, and build community in a relaxed setting. Whether you're attending your first conference or you're a long-time participant, this space is designed to foster conversation, support, and friendship among adults who understand the TSC journey firsthand.
Sponsored by: Beacon Biosignals and Ovid Therapeutics

Young Adults with TSC (ages 17-27), *Spruce 2*
Hosted by: Kylee Lovato
This casual meet-up is a space just for young adults with TSC to connect, share stories, and get to know others navigating similar experiences. Whether you're in school, working, living independently, or still figuring things out—this is a chance to meet peers who understand life with TSC.
Sponsored by: The Family of Keith Hall

Teens and Young Adults with TSC (ages 13-16), *Adams BCD*
Hosted by: Gayle Saunders
This relaxed and fun meet-up is just for teens with TSC to hang out, connect, and get to know others their age who share similar experiences. Whether you're new to the TSC community or have been coming to conferences for years, this is a great chance to make friends, share stories, and feel supported.
Sponsored by: SK Life Science

Parents of Dependent and Semi-Independent Adults with TSC, *Vail*
Hosted by: Dana Holinka
Connect with other parents and caregivers who understand the unique challenges of supporting an adult with TSC. This informal meet-and-greet offers a welcoming space to share experiences, exchange tips, and build a sense of community with others navigating similar journeys—whether your loved one lives at home, with support, or semi-independently.

Parents of Independent Adults with TSC, *Adams BCD*
Hosted by: Denise Lovato
This relaxed meet-and-greet provides an opportunity for parents and caregivers of independent adults with TSC to connect, share successes, challenges, and practical advice. Whether your adult child is living on their own, working, or pursuing their goals, this session offers a supportive space to exchange experiences and build community with others on similar paths.

Parents/Caregivers of Transition-Age Young Adults, *Maple 5*
Hosted by: Shelly Meitzler
This informal meet-and-greet offers parents and caregivers a welcoming space to connect with others who are navigating the transition from adolescence to adulthood, which brings new challenges and opportunities for young adults with TSC and their families. Share experiences, exchange resources, and gain support from a community that understands these unique needs.
Sponsored by: Stanford Medicine Children's Health

Parents of Young Children with TSC (ages 0-13), *Maple 3*
Hosted by: Heather Atkinson
This casual meet-and-greet is a welcoming space for parents and caregivers of young children with TSC to connect, share stories, and support one another. Whether your child is newly diagnosed or you have been managing TSC for years, this is a chance to build community, exchange practical advice, and find comfort in knowing you're not alone on this journey.
Sponsored by: The TAND Clinic at Le Bonheur Children's Hospital and Total Care RX

Grandparents, *Adams BCD*
Hosted by: Mary Ann Lamb and Marilyn Pruce
This relaxed meet-and-greet provides a welcoming space for grandparents to connect, share experiences, and offer support to one another.

Adult and Young Adult Siblings, *Adams BCD*
Hosted by: Riley Grandia and Mikenna McFadden
This casual meet-and-greet offers adult siblings a supportive space to connect, share experiences, and discuss the unique joys and challenges of having a sibling with TSC. Whether you're navigating caregiving roles, family dynamics, or your own personal journey, this session provides an opportunity to build community with others who truly understand.

4:30 p.m. - 6:00 p.m. TSC Clinic Healthcare Providers' Meeting, *Maple 4*
By invitation only.

6:30 p.m. - 8:30 p.m. Opening Dinner, *Adams BCD*
Moderator: Kari Luther Rosbeck
Speakers: Kevin Ess, MD, PhD, Brittany Smith, Chair, TSC Alliance Board of Directors, Pooja Takhar, PhD, Interim Co-Chair, TSCi
Keynote Address: Greg Grunberg
Sponsored by: UCB, Inc.

The official welcome to the 2026 TSC World Conference! The dinner presentation will include opening remarks on conference format and the importance of building connections within the global TSC community. A keynote address will be given by Greg Grunberg on Caregiver Mental Health followed by a tribute to Katie Smith, Director of Government and Global Affairs, on her 20th anniversary at the TSC Alliance and presentation of the Manuel R. Gomez Award.

2026 TSC WORLD CONFERENCE

Friday,

July 31, 2026

Arrive: MCI – DEN; Arrive DEN 3:55 pm; Flight number WN1563

7:00 a.m. - 8:30 a.m.	Breakfast, *Adams BCD* Sponsored by: TSC Alliance Endowment Fund
7:00 a.m. – 3:00 p.m.	Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
8:00 a.m. - 5:00 p.m.	Conference Registration, *Cottonwood Foyer*
8:30 a.m. - 12:00 p.m.	Sibling Workshop (ages 7-12), *Summit 1* Moderator: Elizabeth Skufca Speakers: Abby Turnwald, MS, CGC This engaging, age-appropriate workshop is designed especially for siblings of individuals with TSC. Through a mix of fun activities, games, and guided discussions, children will have the opportunity to connect with peers who share similar experiences in a supportive and welcoming environment. Led by experienced facilitators, the workshop helps participants better understand TSC in a way that makes sense for their age, while also creating space to express feelings, ask questions, and build confidence. Kids will explore topics like family roles, emotions, and ways to support their sibling—all while making new friends and having fun. This is a great opportunity for siblings to feel seen, heard, and supported as an important part of the TSC community.
8:30 a.m. - 10:00 a.m.	KEYNOTE SESSION: TSC Community-Driven Research and Global TAND Collaborations, *Adams A* Moderator: Steven L. Roberds, PhD Community Speaker: Anita Bhatia, MHA Speakers: Dean Aguiar, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Agnies van Eeghen, MD, PhD Sponsored by: TSC Alliance Board and Endowment Fund Board Members This session will showcase the powerful impact achieved through international collaborations, including Anya's Accelerator and the TANDem project, highlighting how research aims to improve the quality of life for people with TSC-Associated Neuropsychiatric Disorders (TAND).
10:30 a.m. - 12:00 p.m.	SECOND BREAKOUT SESSION Dysregulated Behaviors, *Adams A* Moderator: Tanjala Gipson, MD Community Speaker: Sean Shillinger Speakers: Jamie Capal, MD, Peter Davis, MD This session will explore the types and causes of dysregulated behaviors experienced by individuals with TSC from childhood through adulthood. Dysregulated behaviors (i.e., emotional outbursts, aggression, self-injury, difficulty managing frustration/anxiety) are common challenges in TSC. The session will also discuss how behavioral expression may change over time, providing insights into effective support strategies across the lifespan.



Friday (cont.)

Reproductive Decision Making and Childbearing Considerations, *Maple 3*
Moderator: Heather Radtke, MS, CGC
Community Speaker: Iris Mustich, MPH
Speakers: Lara Friel, MD, PhD, Jennifer Glass, LGC, Lyndsay Harshman, MD, MS
Sponsored by: Jack and Danielle Clark

This session will discuss TSC genetics as it relates to relationships, including potential reproductive challenges and considerations. Maternal fetal medicine experts will cover how to navigate reproductive and perinatal health decisions through postpartum, current gaps in consensus guidelines for care, diagnosing TSC in utero and what's on the horizon.

Accessing Early Childhood Services and Non-Medical Therapies, *Spruce 3-4*
Moderator: Shelly Meitzler
Speakers: Joanna Lomas-Mevers, PhD, BCBA-D, Claire Sartwell, BSN, RN

This workshop will discuss the importance of accessing early intervention and preschool services in the United States. This will include discussion of non-medical therapies: physical therapy, occupational therapy, and speech and language therapy.

SEGA Management Over the Lifespan, *Maple 4*
Moderator: Brenda Porter, MD, PhD
Speakers: Asim Choudhri, MD, Daniel Curry, MD, Pradnya Gadgil, MBBS, MRCPCH, Elizabeth Thiele, MD, PhD

In this session, we'll explore how subependymal giant cell astrocytoma (SEGA) management changes over time, including when treatment is needed, how mTOR inhibitors are used, when surgery might be considered, and how monitoring recommendations shift with age.

Transition into Adulthood for Semi-Independent and Dependent Adults: Living Centers and Employment Options, *Maple 5*
Moderator: Mary McDirmid, ChSNC, ChFC
Speakers: Lisa Szilagyi, Deanna Wall, MHA
Sponsored by: Filana Therapeutics, Inc. and MassMutual Special*Care*

This session will provide insights and resources regarding housing and employment options in the United States that incorporate inclusion in the community based on the unique needs of each individual.

Organizing Your Thoughts and Emotions and Managing Relationships (Only open to adults with TSC), *Spruce 2*
Moderator: Shannon and Rob Grandia
Community Speaker: Danielle Clark, MPH, RS, RD, LD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD
Sponsored by: Jack and Danielle Clark

This session features TSC Alliance Regional Adult Support and Resource Leads, guided by clinical expertise, discussing personal and professional experiences related to managing thoughts, emotions and relationships for adults impacted by TSC. The session will also provide insights and resources on executive functioning and tools to help navigate conversations and relationships.

2026 TSC WORLD CONFERENCE

Friday (cont.)

12:00 p.m. - 1:00 p.m.

Lunch, *Adams BCD*
Sponsored by: TSC Alliance Endowment Fund
Optional: Meet the TSC Alliance Board, *Adams, BCD*
Grab your lunch and meet TSC Alliance Board members at designated tables in the lunchroom. Ask questions, hear personal perspectives, and learn more about the TSC Alliance, the role of the Board, and how board members help guide the organization's mission and impact.
Sponsored by: Stewart Smith, and Janice and Julian Gangolli Family

1:00 p.m. - 2:30 p.m.

THIRD BREAKOUT SESSION

Sibling Panel and Discussion (ages 13+), Adams BCD
Speakers: Abby Turnwald, MS, CGC, Mikenna McFadden, Aria Moss

Being a sibling to someone with medical and behavioral needs isn't always easy. If you're 13+, join other TSC siblings for a panel and honest conversation about the challenges, concerns, and experiences that come with the role.

Kidney Tumors, Cysts, and Treatment Options, *Adams A*
Moderator: Chris Kingswood, MD
Speakers: John Bissler, MD, Lyndsay Harshman, MD, MS, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This lecture will focus on kidney issues (i.e., renal angiomyolipomas, cysts, function) and treatment options across all ages.

Mood, Anxiety, and Overactive/Impulsive Behaviors, *Maple 3*
Moderator: Anna Jansen, MD, PhD
Speakers: Jamie Capal, MD, Alice Bryn Salter, MD, Agnies van Eeghen, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This panel will discuss attention deficit hyperactivity disorder (ADHD), anxiety, autism, and the breakthrough research being conducted to better understand how they specifically affect individuals with TSC.

Seizure Action Plans and Rescue Medications, *Spruce 3-4*
Moderator: Vijay Vishwanath, MD, PhD
Speakers: Esteban G., Rob Moss, Raj Rajaraman, MD, MS, Irfan Sheikh, MD
Sponsored by: Neurelis, Inc.

In this workshop, you will hear about the importance of creating a Seizure Action Plan, including the use of rescue medications and how to manage emergencies. Additionally, the session will cover how to communicate the content of a Seizure Action Plan to educational accommodation teams and caregivers, as well as in the workplace. You will leave this session with the start of an actionable plan.

Fetal and Perinatal Health, *Maple 4*
Moderator: Heather Radtke, MS, CGC
Speakers: Allison Divanovic, MD, Stephanie Randle, MD, MS, David Ritter, MD, PhD, Sarah Weatherspoon, MD

TSC can sometimes be detected before birth or in the early newborn period, offering families a unique opportunity to prepare for medical care and support early development. This session will explore the latest knowledge and approaches related to fetal and perinatal health in TSC.

Friday (cont.)

Pre-Puberty and TAND, *Maple 5*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Peter Davis, MD, Shafali Jeste, MD, Joanna Lomas-Mevers, PhD, BCBA-D,
Sponsored by: Biogen

This panel will discuss the transition into puberty and early teenage years which often bring changes in TSC-Associated Neuropsychiatric Disorders (TAND), including heightened anxiety, mood swings, behavioral challenges, attention difficulties, and social struggles.

Preparing Your Family for Epilepsy Surgical Evaluation and Surgery, *Spruce 2*
Moderator: Brenda Porter, MD, PhD
Community Speaker: Lesley Holmes, JD
Speakers: Emilie Hyde, S. Katie Ihnen, MD, PhD, Monika Jones, JD

This discussion offers families a unique and personal perspective on preparing for epilepsy surgical evaluation and surgery led by individuals and caregivers who have firsthand experience with the process.

2:30 p.m. – 3:00 p.m. BREAK

3:00 p.m. - 4:30 p.m. FOURTH BREAKOUT SESSION

Epilepsy Surgery and Brain Imaging, *Adams A*
Moderator: Stephanie Randle, MD, MS
Speakers: Jeffrey Blount, MD, MPH, Dan Curry, MD, Aria Fallah, MD, MS, Jonathan Roth, MD, Wenbo Zhang, MD

Join a panel of epileptologists, neurologists and radiologists as they discuss the vital role of brain imaging in the evaluation and planning of epilepsy surgery for individuals with TSC. Panelists will share insights into various imaging techniques, how these tools guide surgical decisions, and what families can expect throughout the process.

Autism: Diagnosis, Therapy and Managing Behaviors, *Maple 3*
Moderator: Peter Davis, MD, PhD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD, Shafali Jeste, MD, Nicole McDonald, PhD, Mustafa Sahin, MD, PhD
Sponsored by: GondolaBio

Autism spectrum disorder (ASD) is common in individuals with TSC. ASD often presents with a wide range of developmental, communication, and behavioral challenges. This panel brings together clinicians to share diverse perspectives on the diagnosis and management of autism in the context of TSC.

Advocacy and Navigating Education System (Children and Transition-Age), *Spruce 3-4*
Moderator: Elizabeth Skufca
Speakers: Jennifer Flinn, EdD, Lainey Goodwill, JD, Billy Holcombe, PhD, Shelly Meitzler

This workshop session will provide an understanding of an Individualized Education Program (IEP) or 504 plans, goals, progress, and transitions. The session provides tools and insight into the importance of advocating for your child's education at any level. This session will primarily be focused on the North American Educational System.

Managing Progressive Kidney Disease, *Maple 4*
Moderator: Oded Volovelsky, MD, PhD
Speakers: John Bissler, MD, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This session will focus on progressive kidney disease in individuals affected by TSC and the treatment options available to protect kidney function over time.

2026 TSC WORLD CONFERENCE

Friday (cont.)

Living with LAM, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Cori Fratelli, MSN, FNP-C, RN, Nishant Gupta, MD, Joel Moss, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This session addresses oxygen therapy, rehabilitation, and other respiratory therapies that can be used to improve quality of life for those living with lymphangioleiomyomatosis (LAM).

Navigating Issues Living with TSC as an Independent Adult (TAND, Epilepsy, Surveillance), *Spruce 2*
Moderator: Derek Bauer, MD
Speakers: Jamie Capal, MD, David Ritter, MD, PhD
Sponsored by: Jack and Danielle Clark and Lundbeck US

This session will explore the challenges independent adults with TSC may face, including TAND, epilepsy, and ongoing surveillance of TSC throughout adulthood.

4:30 p.m. – 4:45 p.m. BREAK

4:45 p.m. - 5:30 p.m. End of Day Q&A, *Adams A*
Moderator: Shafali Jeste, MD
Speakers: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.



Saturday
August 1, 2026

7:00 a.m. - 8:30 a.m. Breakfast, *Adams BCD*

7:00 a.m. – 3:00 p.m. Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 4:00 p.m. Conference Registration, *Cottonwood Foyer*
8:00 a.m. - 5:00 p.m. Exhibit Hall, *Adams Pre-function*
Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC

8:30 a.m. - 10:00 a.m. KEYNOTE SESSION: Empowering the TSC Community: Research, Treatment, and What Comes Next, *Adams A*
Moderator: Raj Rajaraman, MD, MS
Community Speaker: Bailey Green
Speakers: E. Martina Bebin, MD, MPA, Sergiusz Jóźwiak, MD, PhD, Darcy Krueger, MD, PhD, Lisa Moore-Ramdin, MBBS, MRCPCH, DPM, FFPM, Elizabeth Thiele, MD, PhD
Sponsored by: Lundbeck US and Judy and Mark Schaengold

The impact of TSC research is realized through improved clinical care and better outcomes for individuals living with TSC. This keynote session will explore the essential role of the TSC community in shaping and conducting clinical trials that lead to new treatments and enhanced quality of life. Attendees will gain insights into the clinical trial process, including how to evaluate risk versus benefit, what it means when a trial does not meet its expected endpoints, and learn about upcoming studies on the horizon.

10:00 a.m. – 10:30 a.m. BREAK

10:30 a.m. - 12:00 p.m. FIFTH BREAKOUT SESSION

Future Role of Genetics in Personalized Medicine, *Adams A*
Moderator: Hope Northrup, MD
Speakers: Jeffrey Calhoun, PhD, Laura Farach, MD, Angela Peron, MD, PhD
Sponsored by: Ray Chan

This session explores how advances in genetic research are paving the way for more personalized, effective therapies and clinical care.

Being Proactive with Lifelong Health: Aging and Effects on Brain Health, *Maple 3*
Moderator: Thomas Foutz, MD, PhD
Speakers: Peter Crino, MD, PhD, Andy Liu, MD, MS, Irfan Sheikh, MD

This panel session will provide an overview of changes that can occur as one ages and what can be done to preserve health throughout the lifetime, particularly in regards to brain health.

2026 TSC WORLD CONFERENCE

Saturday (cont.)

Behavioral Plans, *Spruce 3-4*
Moderator: Kim Hindery
Speakers: Kristn Currans, PsyD, Billy Holcombe, PhD, Joanna Lomas-Mevers, PhD, BCBA-D
Sponsored by: Family of Parker Beebe

This hands-on workshop will guide families and caregivers through the process of developing personalized behavioral plans to address behavior challenges found in TSC.

Other Organ Involvement Through the Lifespan: Heart, Eyes, Liver, and Pancreas, *Maple 4*
Moderator: Kate Richardson, MS, CGC
Speakers: Rod Foroozan, MD, David Ritter, MD, PhD, David Rodriguez-Buritica, MD

This session will discuss tumors associated with TSC, including liver and retinal hamartomas, pancreatic neuroendocrine tumors, and non-malignant tumors in the heart. The panelists will also provide general recommendations on monitoring these organs and treating tumors.

Sleep, *Maple 5*
Moderator: Zacil Vilchis, MD, MSc
Speakers: Stacey Bissell, PhD, Jonathan Lipton, MD, PhD, Donald Phillips, MD, MPH, FACNS
Sponsored by: PsychoGenics Inc.

This discussion will cover sleep difficulties that are common among individuals with TSC and can significantly impact the quality of life for both the individual and their family. This session will offer insights, strategies, and support to improve sleep health.

Caregiver Resources: Self and Respite Care, *Spruce 2*
Moderator: Chris Kingswood, MD
Speakers: Gil Amit, MA, Lilian Ansari, Liezl Schlebusch, PhD

This session will address resources and strategies for managing the stress TSC can bring to a caregiver's life, including tactics for improving your physical and mental health, small steps of self-care for daily life, and information on accessing respite care.

12:00 p.m. - 1:00 p.m. Lunch, *Adams BC*
Sponsored by: Friends of Eric Parkes
Optional: Volunteer Connections & Leadership Opportunities, *Adams D*
Grab your lunch and stop by to connect with volunteer leaders, event hosts and community advocates from across the United States. Hear personal stories, explore opportunities in advocacy, awareness, fundraising, and peer support, and discover how your skills and experiences can make a meaningful impact.

1:00 p.m. - 2:30 p.m. SIXTH BREAKOUT SESSION

Genetic Therapies: Hopes and Hurdles, *Adams A*
Moderator: Elizabeth Thiele, MD, PhD
Speakers: Clayton Beard, PhD, Mark Hester, PhD, Julian Martinez-Agosto, MD, PhD, FACMG, Andrew Steinsapir, MBA
Sponsored by: Biogen and Regeneron

This session will explore the possibilities for genetic therapies in TSC and the challenges researchers face to make it a reality.



Saturday (cont.)

SUDEP Risk and Seizure Monitoring Technology, *Maple 3*
Moderator: James Wheless, MD
Speakers: Peter Crino, MD, PhD, Mary Duffy, Bernice Martin Lee, Donald Phillips, MD, MPH, FACNS

This panel discussion will cover the risks that may contribute to sudden unexpected death in epilepsy (SUDEP) and how technology can help mitigate some of the risks. Content Warning: this is a challenging topic that may include an emotional trigger.

Caregiver Wellbeing, *Spruce 3-4*
Moderator: Katie Smith
Speakers: Anna Jansen, MD, PhD, Liezl Schlebusch, PhD
Sponsored by: Keenova Therapeutics

Caregivers of individuals with TSC report both joys and challenges in their caregiving role. Studies have shown that sometimes these challenges can impact caregiver well-being and family quality of life. This session will help give caregivers tools needed deal with the many thoughts and feelings they experience on a daily basis, using Acceptance and Commitment Therapy (ACT).

Navigating Insurance and Specialty Pharmacy, *Maple 4*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Richard Faris, PhD, Jessica Krefting, BSN, RN, Claire Sartwell, BSN, RN
Sponsored by: PANTHERx Rare Pharmacy

Navigating the United States insurance coverage and specialty pharmacy processes can be challenging, especially when managing treatments for TSC. This workshop provides practical guidance on understanding insurance benefits, prior authorizations, copay assistance, and working effectively with specialty pharmacies.

Health Issues for Women with TSC, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Lara Friel, MD, PhD, Mark Keezer, MDCM, PhD, Kate Richardson, MS, CGC
Sponsored by: Jack and Danielle Clark

Women with TSC face unique health concerns throughout adulthood that may be influenced by hormones, reproductive health, and the progression of TSC-related conditions. This session will explore the intersection of TSC and women's health, providing guidance on managing health across all stages of adult life.

Navigating the Education System for a High School Certificate, *Spruce 2*
Moderator: Jennifer Flinn, EdD
Speakers: Lilian Ansari, Kate Crossett, Elizabeth Skufca

Understanding how to navigate the education system in the United States is essential to supporting academic success and long-term goals. This session will focus on how to work with schools to pursue a high school certificate pathway, an important achievement for many students with learning differences.

2026 TSC WORLD CONFERENCE

Saturday (cont.)

3:00 p.m. - 4:30 p.m. SEVENTH BREAKOUT SESSION

Taking an Active Role in Government Advocacy: State and Federal, *Adams A*
Moderator: Sara Chieffo
Speakers: Morgan Corder, Margaret Cox, Peter Crino, MD, PhD, Allison Hulme, PhD, Mark Vieth, Laura Weidner, JD

The TSC Alliance is proud of the incredible grassroots advocacy program that has been working to ensure United States federal and state funding of research in TSC. This session will cover the many ways different stakeholders advocate for TSC research funding at the federal and state levels, and how you can get involved.

Overview of TAND Medications for Harmful and Disruptive Behaviors, *Maple 3*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Jay Salpekar, MD, FANPA

This session will focus on medication options for behavioral issues that are commonly associated with TSC and TAND.

Transition into Adulthood for Independent Adults: Preparing for Employment and Higher Education, *Spruce 3-4*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Iris Mustich, MPH

This session will provide insights and resources for young adults impacted by TSC and their families to approach the challenges of transitions to adulthood. The group will share their personal experiences and key considerations for independent individuals impacted by TSC who are transitioning out of secondary school and into higher education or employment.

Refractory Seizure Management and Tools, *Maple 4*
Moderator: Rohini Coorg, MD
Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Rob Moss, Irfan Sheikh, MD, James Wheless, MD
Sponsored by: Aeovian Pharmaceuticals, GRIN Therapeutics, LivaNova, and Lundbeck US

Epilepsy in TSC can often be resistant to medication (refractory). Seizures may not be controlled with initial therapies, resulting in the need to be aware of all possible therapeutic options to treat seizures in a person with TSC. This session will explore other treatment options neurologists may discuss with families and individuals with TSC of any age to try to bring seizures under control.

Skin and Dental Manifestations and Treatment Options, *Maple 5*
Moderator: Thomas Darling, MD, PhD
Speakers: Elizabeth Gosnell, DMD, MS, Deeti Pithadia, MD

This lecture will address skin and dental manifestations of TSC and how to treat them, and include strategies for treating those with intellectual disabilities.

Medical and School Records, Organizing Documents, EMR, *Spruce 2*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Reiko Donato, Jessica Krefting, BSN, RN

Managing care for someone with TSC often means keeping track of medical records, school documents, evaluations, IEPs, and test results—which can quickly become overwhelming. This practical discussion session will help families learn how to organize, store, and access important information to better coordinate care and advocate for services.

Saturday (cont.)

4:30 p.m. – 4:45 p.m.	BREAK
4:45 p.m. - 5:30 p.m.	End of Day Q&A and Closing Remarks, *Adams A* Moderator: Steven L. Roberds, PhD Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.
6:30 p.m. - 10:00 p.m.	Blue Night: Closing Dinner honoring Steve and Mary Roberds, *Adams BCD* Emcees: Jim O'Heir and Kari Luther Rosbeck Sponsored by: Joy and Chris Dinsdale Entertainment Sponsor: TSC Alliance Staff Be sure to wear blue for the Blue Night Dinner as we close out the Conference! During dinner, we will recognize TSC Alliance Chief Scientific Officer Steven L. Roberds, PhD, and his wife Mary Roberds for their incredible contributions to the TSC Alliance.

Sunday, August 2, 2026:

Depart: DEN – MCI; Depart DEN 6:10 AM; Flight WN1584

Conference Session Content

Session Types

Keynote/General Sessions (recorded) will feature 3-4 speakers with a moderator and include formal presentations on topics that impact individuals across the lifespan with some time at the end for Q&A.

Panel Presentations (recorded) will feature 3-4 speakers with a moderator who will ask questions to engage interactive conversation amongst the panel and the attendees.

Workshops (non-recorded) are interactive working groups featuring 3-4 speakers, a moderator, and a key take-away learning objective with supporting materials.

Specialty Topic Lectures (recorded) will feature 2+ speakers with a moderator to focus on specialty topics that affect the TSC community.

Discussion Groups (non-recorded) will feature 2-3 speakers and a moderator to discuss more personal topics that affect the TSC community in a closed setting.

End of Day Q&A Sessions, Adams A
The 2026 TSC World Conference includes two end-of-day Question and Answer Sessions. These sessions feature TSC experts who are available for general discussion and questions on any topics related to TSC.

- Friday, July 31: 4:45 to 5:30 p.m.
  Moderator: Shafali Jeste, MD
  Panelists: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

- Saturday, August 1: 4:45 to 5:30 p.m.
  Moderator: Steve Roberds, PhD
  Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD



2026 TSC WORLD CONFERENCE

Agenda and Session Descriptions

Wednesday
July 29, 2026

12:00 p.m. - 6:00 p.m.	Conference Registration, *Cottonwood Foyer*

Thursday
July 30, 2026

7:00 a.m. - 3:00 p.m.	Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 6:00 p.m.	Conference Registration, *Cottonwood Foyer*
12:00 p.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC Research Room, *Spruce 1*
1:00 p.m. - 2:30 p.m.	OPENING KEYNOTE: The State of TSC Around the World, *Adams A* Moderator: Pradnya Gadgil, MBBS, MRCPCH Community Speaker: Jennifer Flinn, EdD Speakers: Kevin Ess, MD, PhD, Anna Jansen, MD, PhD, Kari Luther Rosbeck Sponsored by: Filana Therapeutics, Inc. Kick off the conference with an inspiring keynote that takes you on a journey across continents, offering a dynamic, big-picture view of tuberous sclerosis complex (TSC) research and care worldwide.
2:30 p.m. - 2:45 p.m.	BREAK
2:45 p.m. - 4:15 p.m.	FIRST BREAKOUT SESSION Seizure Treatments, *Adams A* Moderator: Priya Tatachar, MD Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Peter Crino, MD, PhD, Rod Foroozan, MD, Thomas Foutz, MD, PhD, Darcy Krueger, MD, PhD Sponsored by: Filana Therapeutics, Inc., LivaNova, and Montara Therapeutics This session will address seizure treatments available across all ages, as well as discussion about updated guidelines for the use of vigabatrin.

Federal Assistance Programs and Special Needs Trusts, *Maple 3*
Moderator: Tammy Thorne
Speakers: Deanna Eble, Esq., Lainey Goodwill, JD, Mary McDirmid, ChSNC, ChFC
Sponsored by: MassMutual Special*Care*

This panel session will discuss the transition from childhood to adulthood and the services and supports needed for dependent adults, including their future financial and daily living needs and the timelines and common issues around these processes. The session includes perspectives from US based financial and legal experts, as well as TSC community members.

TSC 101 for Ages 8-17, *Spruce 3-4*
Moderator: Mikenna McFadden
Speakers: Emily Docktor, LMSW, Jennifer Glass, LGC
Sponsored by: Chemistry Rx

Through age-appropriate discussion and interactive activities, this workshop will help children and teens living with TSC and their siblings understand what TSC is and learn how it affects the body, brain, and daily life.

Treatment Options and Clinical Trials in LAM, *Maple 4*
Moderator: Joel Moss, MD, PhD
Community Speaker: Gwen Pryor
Speakers: Greg Downey, MD, FRCPC, Elizabeth (Lisa) Henske, MD, Simon Johnson, DM, FCRP
Sponsored by: Praxis Precision Medicines

This session addresses the link between TSC and lymphangioleiomyomatosis (LAM). Learn about treatment options, available clinical trials, and resources and support available for those with LAM.

Sexual Development for Dependent and Semi-Independent TSC Adults, *Maple 5*
Moderator: Fábio Nascimento, MD
Speakers: Agnies van Eeghen, MD, PhD

This session will explore the important but often overlooked topic of sexual development in individuals with TSC who are dependent or semi-independent. As individuals with TSC move into adolescence and adulthood, they experience the same physical and emotional changes as their peers but may face unique challenges when it comes to communication, boundaries, education, and safety.

Men's Health Issues for Adults with TSC, *Spruce 2*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Mark Keezer, MDCM, PhD, Joshua Samuels, MD, MPH

As men with TSC move through adulthood, they may face specific health concerns that are often overlooked. This session focuses on the unique medical, neurological, and psychosocial aspects of living with TSC as an adult male.

4:15 p.m. – 4:30 p.m. BREAK

2026 TSC WORLD CONFERENCE

Thursday (cont.)

4:30 p.m. - 6:00 p.m. MEET AND GREET OPPORTUNITIES

Adults with TSC (ages 28+), *Spruce 2*
Hosted by: Kate Crossett and Seth Fritts
This casual, peer-focused gathering is an opportunity for adults with TSC (age 28 and up) to connect, share experiences, and build community in a relaxed setting. Whether you're attending your first conference or you're a long-time participant, this space is designed to foster conversation, support, and friendship among adults who understand the TSC journey firsthand.
Sponsored by: Beacon Biosignals and Ovid Therapeutics

Young Adults with TSC (ages 17-27), *Spruce 2*
Hosted by: Kylee Lovato
This casual meet-up is a space just for young adults with TSC to connect, share stories, and get to know others navigating similar experiences. Whether you're in school, working, living independently, or still figuring things out—this is a chance to meet peers who understand life with TSC.
Sponsored by: The Family of Keith Hall

Teens and Young Adults with TSC (ages 13-16), *Adams BCD*
Hosted by: Gayle Saunders
This relaxed and fun meet-up is just for teens with TSC to hang out, connect, and get to know others their age who share similar experiences. Whether you're new to the TSC community or have been coming to conferences for years, this is a great chance to make friends, share stories, and feel supported.
Sponsored by: SK Life Science

Parents of Dependent and Semi-Independent Adults with TSC, *Vail*
Hosted by: Dana Holinka
Connect with other parents and caregivers who understand the unique challenges of supporting an adult with TSC. This informal meet-and-greet offers a welcoming space to share experiences, exchange tips, and build a sense of community with others navigating similar journeys—whether your loved one lives at home, with support, or semi-independently.

Parents of Independent Adults with TSC, *Adams BCD*
Hosted by: Denise Lovato
This relaxed meet-and-greet provides an opportunity for parents and caregivers of independent adults with TSC to connect, share successes, challenges, and practical advice. Whether your adult child is living on their own, working, or pursuing their goals, this session offers a supportive space to exchange experiences and build community with others on similar paths.

Parents/Caregivers of Transition-Age Young Adults, *Maple 5*
Hosted by: Shelly Meitzler
This informal meet-and-greet offers parents and caregivers a welcoming space to connect with others who are navigating the transition from adolescence to adulthood, which brings new challenges and opportunities for young adults with TSC and their families. Share experiences, exchange resources, and gain support from a community that understands these unique needs.
Sponsored by: Stanford Medicine Children's Health

Parents of Young Children with TSC (ages 0-13), *Maple 3*
Hosted by: Heather Atkinson
This casual meet-and-greet is a welcoming space for parents and caregivers of young children with TSC to connect, share stories, and support one another. Whether your child is newly diagnosed or you have been managing TSC for years, this is a chance to build community, exchange practical advice, and find comfort in knowing you're not alone on this journey.
Sponsored by: The TAND Clinic at Le Bonheur Children's Hospital and Total Care RX

Grandparents, *Adams BCD*
Hosted by: Mary Ann Lamb and Marilyn Pruce
This relaxed meet-and-greet provides a welcoming space for grandparents to connect, share experiences, and offer support to one another.

Adult and Young Adult Siblings, *Adams BCD*
Hosted by: Riley Grandia and Mikenna McFadden
This casual meet-and-greet offers adult siblings a supportive space to connect, share experiences, and discuss the unique joys and challenges of having a sibling with TSC. Whether you're navigating caregiving roles, family dynamics, or your own personal journey, this session provides an opportunity to build community with others who truly understand.

4:30 p.m. - 6:00 p.m. TSC Clinic Healthcare Providers' Meeting, *Maple 4*
By invitation only.

6:30 p.m. - 8:30 p.m. Opening Dinner, *Adams BCD*
Moderator: Kari Luther Rosbeck
Speakers: Kevin Ess, MD, PhD, Brittany Smith, Chair, TSC Alliance Board of Directors, Pooja Takhar, PhD, Interim Co-Chair, TSCi
Keynote Address: Greg Grunberg
Sponsored by: UCB, Inc.

The official welcome to the 2026 TSC World Conference! The dinner presentation will include opening remarks on conference format and the importance of building connections within the global TSC community. A keynote address will be given by Greg Grunberg on Caregiver Mental Health followed by a tribute to Katie Smith, Director of Government and Global Affairs, on her 20th anniversary at the TSC Alliance and presentation of the Manuel R. Gomez Award.

2026 TSC WORLD CONFERENCE

Friday,

July 31, 2026

Arrive: MCI – DEN; Arrive DEN 3:55 pm; Flight number WN1563

7:00 a.m. - 8:30 a.m.	Breakfast, *Adams BCD* Sponsored by: TSC Alliance Endowment Fund
7:00 a.m. – 3:00 p.m.	Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
8:00 a.m. - 5:00 p.m.	Conference Registration, *Cottonwood Foyer*
8:30 a.m. - 12:00 p.m.	Sibling Workshop (ages 7-12), *Summit 1* Moderator: Elizabeth Skufca Speakers: Abby Turnwald, MS, CGC This engaging, age-appropriate workshop is designed especially for siblings of individuals with TSC. Through a mix of fun activities, games, and guided discussions, children will have the opportunity to connect with peers who share similar experiences in a supportive and welcoming environment. Led by experienced facilitators, the workshop helps participants better understand TSC in a way that makes sense for their age, while also creating space to express feelings, ask questions, and build confidence. Kids will explore topics like family roles, emotions, and ways to support their sibling—all while making new friends and having fun. This is a great opportunity for siblings to feel seen, heard, and supported as an important part of the TSC community.
8:30 a.m. - 10:00 a.m.	KEYNOTE SESSION: TSC Community-Driven Research and Global TAND Collaborations, *Adams A* Moderator: Steven L. Roberds, PhD Community Speaker: Anita Bhatia, MHA Speakers: Dean Aguiar, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Agnies van Eeghen, MD, PhD Sponsored by: TSC Alliance Board and Endowment Fund Board Members This session will showcase the powerful impact achieved through international collaborations, including Anya's Accelerator and the TANDem project, highlighting how research aims to improve the quality of life for people with TSC-Associated Neuropsychiatric Disorders (TAND).
10:30 a.m. - 12:00 p.m.	SECOND BREAKOUT SESSION Dysregulated Behaviors, *Adams A* Moderator: Tanjala Gipson, MD Community Speaker: Sean Shillinger Speakers: Jamie Capal, MD, Peter Davis, MD This session will explore the types and causes of dysregulated behaviors experienced by individuals with TSC from childhood through adulthood. Dysregulated behaviors (i.e., emotional outbursts, aggression, self-injury, difficulty managing frustration/anxiety) are common challenges in TSC. The session will also discuss how behavioral expression may change over time, providing insights into effective support strategies across the lifespan.

Friday (cont.)

Reproductive Decision Making and Childbearing Considerations, *Maple 3*
Moderator: Heather Radtke, MS, CGC
Community Speaker: Iris Mustich, MPH
Speakers: Lara Friel, MD, PhD, Jennifer Glass, LGC, Lyndsay Harshman, MD, MS
Sponsored by: Jack and Danielle Clark

This session will discuss TSC genetics as it relates to relationships, including potential reproductive challenges and considerations. Maternal fetal medicine experts will cover how to navigate reproductive and perinatal health decisions through postpartum, current gaps in consensus guidelines for care, diagnosing TSC in utero and what's on the horizon.

Accessing Early Childhood Services and Non-Medical Therapies, *Spruce 3-4*
Moderator: Shelly Meitzler
Speakers: Joanna Lomas-Mevers, PhD, BCBA-D, Claire Sartwell, BSN, RN

This workshop will discuss the importance of accessing early intervention and preschool services in the United States. This will include discussion of non-medical therapies: physical therapy, occupational therapy, and speech and language therapy.

SEGA Management Over the Lifespan, *Maple 4*
Moderator: Brenda Porter, MD, PhD
Speakers: Asim Choudhri, MD, Daniel Curry, MD, Pradnya Gadgil, MBBS, MRCPCH, Elizabeth Thiele, MD, PhD

In this session, we'll explore how subependymal giant cell astrocytoma (SEGA) management changes over time, including when treatment is needed, how mTOR inhibitors are used, when surgery might be considered, and how monitoring recommendations shift with age.

Transition into Adulthood for Semi-Independent and Dependent Adults: Living Centers and Employment Options, *Maple 5*
Moderator: Mary McDirmid, ChSNC, ChFC
Speakers: Lisa Szilagyi, Deanna Wall, MHA
Sponsored by: Filana Therapeutics, Inc. and MassMutual Special*Care*

This session will provide insights and resources regarding housing and employment options in the United States that incorporate inclusion in the community based on the unique needs of each individual.

Organizing Your Thoughts and Emotions and Managing Relationships (Only open to adults with TSC), *Spruce 2*
Moderator: Shannon and Rob Grandia
Community Speaker: Danielle Clark, MPH, RS, RD, LD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD
Sponsored by: Jack and Danielle Clark

This session features TSC Alliance Regional Adult Support and Resource Leads, guided by clinical expertise, discussing personal and professional experiences related to managing thoughts, emotions and relationships for adults impacted by TSC. The session will also provide insights and resources on executive functioning and tools to help navigate conversations and relationships.

2026 TSC WORLD CONFERENCE

Friday (cont.)

12:00 p.m. - 1:00 p.m.

Lunch, *Adams BCD*
Sponsored by: TSC Alliance Endowment Fund
Optional: Meet the TSC Alliance Board, *Adams, BCD*
Grab your lunch and meet TSC Alliance Board members at designated tables in the lunchroom. Ask questions, hear personal perspectives, and learn more about the TSC Alliance, the role of the Board, and how board members help guide the organization's mission and impact.
Sponsored by: Stewart Smith, and Janice and Julian Gangolli Family

1:00 p.m. - 2:30 p.m.

THIRD BREAKOUT SESSION

Sibling Panel and Discussion (ages 13+), Adams BCD
Speakers: Abby Turnwald, MS, CGC, Mikenna McFadden, Aria Moss

Being a sibling to someone with medical and behavioral needs isn't always easy. If you're 13+, join other TSC siblings for a panel and honest conversation about the challenges, concerns, and experiences that come with the role.

Kidney Tumors, Cysts, and Treatment Options, *Adams A*
Moderator: Chris Kingswood, MD
Speakers: John Bissler, MD, Lyndsay Harshman, MD, MS, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This lecture will focus on kidney issues (i.e., renal angiomyolipomas, cysts, function) and treatment options across all ages.

Mood, Anxiety, and Overactive/Impulsive Behaviors, *Maple 3*
Moderator: Anna Jansen, MD, PhD
Speakers: Jamie Capal, MD, Alice Bryn Salter, MD, Agnies van Eeghen, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This panel will discuss attention deficit hyperactivity disorder (ADHD), anxiety, autism, and the breakthrough research being conducted to better understand how they specifically affect individuals with TSC.

Seizure Action Plans and Rescue Medications, *Spruce 3-4*
Moderator: Vijay Vishwanath, MD, PhD
Speakers: Esteban G., Rob Moss, Raj Rajaraman, MD, MS, Irfan Sheikh, MD
Sponsored by: Neurelis, Inc.

In this workshop, you will hear about the importance of creating a Seizure Action Plan, including the use of rescue medications and how to manage emergencies. Additionally, the session will cover how to communicate the content of a Seizure Action Plan to educational accommodation teams and caregivers, as well as in the workplace. You will leave this session with the start of an actionable plan.

Fetal and Perinatal Health, *Maple 4*
Moderator: Heather Radtke, MS, CGC
Speakers: Allison Divanovic, MD, Stephanie Randle, MD, MS, David Ritter, MD, PhD, Sarah Weatherspoon, MD

TSC can sometimes be detected before birth or in the early newborn period, offering families a unique opportunity to prepare for medical care and support early development. This session will explore the latest knowledge and approaches related to fetal and perinatal health in TSC.

Friday (cont.)

Pre-Puberty and TAND, *Maple 5*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Peter Davis, MD, Shafali Jeste, MD, Joanna Lomas-Mevers, PhD, BCBA-D,
Sponsored by: Biogen

This panel will discuss the transition into puberty and early teenage years which often bring changes in TSC-Associated Neuropsychiatric Disorders (TAND), including heightened anxiety, mood swings, behavioral challenges, attention difficulties, and social struggles.

Preparing Your Family for Epilepsy Surgical Evaluation and Surgery, *Spruce 2*
Moderator: Brenda Porter, MD, PhD
Community Speaker: Lesley Holmes, JD
Speakers: Emilie Hyde, S. Katie Ihnen, MD, PhD, Monika Jones, JD

This discussion offers families a unique and personal perspective on preparing for epilepsy surgical evaluation and surgery led by individuals and caregivers who have firsthand experience with the process.

2:30 p.m. – 3:00 p.m. BREAK

3:00 p.m. - 4:30 p.m. FOURTH BREAKOUT SESSION

Epilepsy Surgery and Brain Imaging, *Adams A*
Moderator: Stephanie Randle, MD, MS
Speakers: Jeffrey Blount, MD, MPH, Dan Curry, MD, Aria Fallah, MD, MS, Jonathan Roth, MD, Wenbo Zhang, MD

Join a panel of epileptologists, neurologists and radiologists as they discuss the vital role of brain imaging in the evaluation and planning of epilepsy surgery for individuals with TSC. Panelists will share insights into various imaging techniques, how these tools guide surgical decisions, and what families can expect throughout the process.

Autism: Diagnosis, Therapy and Managing Behaviors, *Maple 3*
Moderator: Peter Davis, MD, PhD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD, Shafali Jeste, MD, Nicole McDonald, PhD, Mustafa Sahin, MD, PhD
Sponsored by: GondolaBio

Autism spectrum disorder (ASD) is common in individuals with TSC. ASD often presents with a wide range of developmental, communication, and behavioral challenges. This panel brings together clinicians to share diverse perspectives on the diagnosis and management of autism in the context of TSC.

Advocacy and Navigating Education System (Children and Transition-Age), *Spruce 3-4*
Moderator: Elizabeth Skufca
Speakers: Jennifer Flinn, EdD, Lainey Goodwill, JD, Billy Holcombe, PhD, Shelly Meitzler

This workshop session will provide an understanding of an Individualized Education Program (IEP) or 504 plans, goals, progress, and transitions. The session provides tools and insight into the importance of advocating for your child's education at any level. This session will primarily be focused on the North American Educational System.

Managing Progressive Kidney Disease, *Maple 4*
Moderator: Oded Volovelsky, MD, PhD
Speakers: John Bissler, MD, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This session will focus on progressive kidney disease in individuals affected by TSC and the treatment options available to protect kidney function over time.

2026 TSC WORLD CONFERENCE

Friday (cont.)

Living with LAM, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Cori Fratelli, MSN, FNP-C, RN, Nishant Gupta, MD, Joel Moss, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This session addresses oxygen therapy, rehabilitation, and other respiratory therapies that can be used to improve quality of life for those living with lymphangioleiomyomatosis (LAM).

Navigating Issues Living with TSC as an Independent Adult (TAND, Epilepsy, Surveillance), *Spruce 2*
Moderator: Derek Bauer, MD
Speakers: Jamie Capal, MD, David Ritter, MD, PhD
Sponsored by: Jack and Danielle Clark and Lundbeck US

This session will explore the challenges independent adults with TSC may face, including TAND, epilepsy, and ongoing surveillance of TSC throughout adulthood.

4:30 p.m. – 4:45 p.m. BREAK

4:45 p.m. - 5:30 p.m. End of Day Q&A, *Adams A*
Moderator: Shafali Jeste, MD
Speakers: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.



Saturday
August 1, 2026

7:00 a.m. - 8:30 a.m.	Breakfast, *Adams BCD*
7:00 a.m. – 3:00 p.m.	Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 4:00 p.m.	Conference Registration, *Cottonwood Foyer*
8:00 a.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
8:30 a.m. - 10:00 a.m.	KEYNOTE SESSION: Empowering the TSC Community: Research, Treatment, and What Comes Next, *Adams A* Moderator: Raj Rajaraman, MD, MS Community Speaker: Bailey Green Speakers: E. Martina Bebin, MD, MPA, Sergiusz Jóźwiak, MD, PhD, Darcy Krueger, MD, PhD, Lisa Moore-Ramdin, MBBS, MRCPCH, DPM, FFPM, Elizabeth Thiele, MD, PhD Sponsored by: Lundbeck US and Judy and Mark Schaengold The impact of TSC research is realized through improved clinical care and better outcomes for individuals living with TSC. This keynote session will explore the essential role of the TSC community in shaping and conducting clinical trials that lead to new treatments and enhanced quality of life. Attendees will gain insights into the clinical trial process, including how to evaluate risk versus benefit, what it means when a trial does not meet its expected endpoints, and learn about upcoming studies on the horizon.
10:00 a.m. – 10:30 a.m.	BREAK
10:30 a.m. - 12:00 p.m.	FIFTH BREAKOUT SESSION Future Role of Genetics in Personalized Medicine, *Adams A* Moderator: Hope Northrup, MD Speakers: Jeffrey Calhoun, PhD, Laura Farach, MD, Angela Peron, MD, PhD Sponsored by: Ray Chan This session explores how advances in genetic research are paving the way for more personalized, effective therapies and clinical care. Being Proactive with Lifelong Health: Aging and Effects on Brain Health, *Maple 3* Moderator: Thomas Foutz, MD, PhD Speakers: Peter Crino, MD, PhD, Andy Liu, MD, MS, Irfan Sheikh, MD This panel session will provide an overview of changes that can occur as one ages and what can be done to preserve health throughout the lifetime, particularly in regards to brain health.

2026 TSC WORLD CONFERENCE

Saturday (cont.)

Behavioral Plans, *Spruce 3-4*
Moderator: Kim Hindery
Speakers: Kristn Currans, PsyD, Billy Holcombe, PhD, Joanna Lomas-Mevers, PhD, BCBA-D
Sponsored by: Family of Parker Beebe

This hands-on workshop will guide families and caregivers through the process of developing personalized behavioral plans to address behavior challenges found in TSC.

Other Organ Involvement Through the Lifespan: Heart, Eyes, Liver, and Pancreas, *Maple 4*
Moderator: Kate Richardson, MS, CGC
Speakers: Rod Foroozan, MD, David Ritter, MD, PhD, David Rodriguez-Buritica, MD

This session will discuss tumors associated with TSC, including liver and retinal hamartomas, pancreatic neuroendocrine tumors, and non-malignant tumors in the heart. The panelists will also provide general recommendations on monitoring these organs and treating tumors.

Sleep, *Maple 5*
Moderator: Zacil Vilchis, MD, MSc
Speakers: Stacey Bissell, PhD, Jonathan Lipton, MD, PhD, Donald Phillips, MD, MPH, FACNS
Sponsored by: PsychoGenics Inc.

This discussion will cover sleep difficulties that are common among individuals with TSC and can significantly impact the quality of life for both the individual and their family. This session will offer insights, strategies, and support to improve sleep health.

Caregiver Resources: Self and Respite Care, *Spruce 2*
Moderator: Chris Kingswood, MD
Speakers: Gil Amit, MA, Lilian Ansari, Liezl Schlebusch, PhD

This session will address resources and strategies for managing the stress TSC can bring to a caregiver's life, including tactics for improving your physical and mental health, small steps of self-care for daily life, and information on accessing respite care.

12:00 p.m. - 1:00 p.m.

Lunch, *Adams BC*
Sponsored by: Friends of Eric Parkes
Optional: Volunteer Connections & Leadership Opportunities, *Adams D*
Grab your lunch and stop by to connect with volunteer leaders, event hosts and community advocates from across the United States. Hear personal stories, explore opportunities in advocacy, awareness, fundraising, and peer support, and discover how your skills and experiences can make a meaningful impact.

1:00 p.m. - 2:30 p.m.

SIXTH BREAKOUT SESSION

Genetic Therapies: Hopes and Hurdles, *Adams A*
Moderator: Elizabeth Thiele, MD, PhD
Speakers: Clayton Beard, PhD, Mark Hester, PhD, Julian Martinez-Agosto, MD, PhD, FACMG, Andrew Steinsapir, MBA
Sponsored by: Biogen and Regeneron

This session will explore the possibilities for genetic therapies in TSC and the challenges researchers face to make it a reality.

Saturday (cont.)

SUDEP Risk and Seizure Monitoring Technology, *Maple 3*
Moderator: James Wheless, MD
Speakers: Peter Crino, MD, PhD, Mary Duffy, Bernice Martin Lee, Donald Phillips, MD, MPH, FACNS

This panel discussion will cover the risks that may contribute to sudden unexpected death in epilepsy (SUDEP) and how technology can help mitigate some of the risks. Content Warning: this is a challenging topic that may include an emotional trigger.

Caregiver Wellbeing, *Spruce 3-4*
Moderator: Katie Smith
Speakers: Anna Jansen, MD, PhD, Liezl Schlebusch, PhD
Sponsored by: Keenova Therapeutics

Caregivers of individuals with TSC report both joys and challenges in their caregiving role. Studies have shown that sometimes these challenges can impact caregiver well-being and family quality of life. This session will help give caregivers tools needed deal with the many thoughts and feelings they experience on a daily basis, using Acceptance and Commitment Therapy (ACT).

Navigating Insurance and Specialty Pharmacy, *Maple 4*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Richard Faris, PhD, Jessica Krefting, BSN, RN, Claire Sartwell, BSN, RN
Sponsored by: PANTHERx Rare Pharmacy

Navigating the United States insurance coverage and specialty pharmacy processes can be challenging, especially when managing treatments for TSC. This workshop provides practical guidance on understanding insurance benefits, prior authorizations, copay assistance, and working effectively with specialty pharmacies.

Health Issues for Women with TSC, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Lara Friel, MD, PhD, Mark Keezer, MDCM, PhD, Kate Richardson, MS, CGC
Sponsored by: Jack and Danielle Clark

Women with TSC face unique health concerns throughout adulthood that may be influenced by hormones, reproductive health, and the progression of TSC-related conditions. This session will explore the intersection of TSC and women's health, providing guidance on managing health across all stages of adult life.

Navigating the Education System for a High School Certificate, *Spruce 2*
Moderator: Jennifer Flinn, EdD
Speakers: Lilian Ansari, Kate Crossett, Elizabeth Skufca

Understanding how to navigate the education system in the United States is essential to supporting academic success and long-term goals. This session will focus on how to work with schools to pursue a high school certificate pathway, an important achievement for many students with learning differences.

2026 TSC WORLD CONFERENCE

Saturday (cont.)

3:00 p.m. - 4:30 p.m. SEVENTH BREAKOUT SESSION

Taking an Active Role in Government Advocacy: State and Federal, *Adams A*
Moderator: Sara Chieffo
Speakers: Morgan Corder, Margaret Cox, Peter Crino, MD, PhD, Allison Hulme, PhD, Mark Vieth, Laura Weidner, JD

The TSC Alliance is proud of the incredible grassroots advocacy program that has been working to ensure United States federal and state funding of research in TSC. This session will cover the many ways different stakeholders advocate for TSC research funding at the federal and state levels, and how you can get involved.

Overview of TAND Medications for Harmful and Disruptive Behaviors, *Maple 3*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Jay Salpekar, MD, FANPA

This session will focus on medication options for behavioral issues that are commonly associated with TSC and TAND.

Transition into Adulthood for Independent Adults: Preparing for Employment and Higher Education, *Spruce 3-4*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Iris Mustich, MPH

This session will provide insights and resources for young adults impacted by TSC and their families to approach the challenges of transitions to adulthood. The group will share their personal experiences and key considerations for independent individuals impacted by TSC who are transitioning out of secondary school and into higher education or employment.

Refractory Seizure Management and Tools, *Maple 4*
Moderator: Rohini Coorg, MD
Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Rob Moss, Irfan Sheikh, MD, James Wheless, MD
Sponsored by: Aeovian Pharmaceuticals, GRIN Therapeutics, LivaNova, and Lundbeck US

Epilepsy in TSC can often be resistant to medication (refractory). Seizures may not be controlled with initial therapies, resulting in the need to be aware of all possible therapeutic options to treat seizures in a person with TSC. This session will explore other treatment options neurologists may discuss with families and individuals with TSC of any age to try to bring seizures under control.

Skin and Dental Manifestations and Treatment Options, *Maple 5*
Moderator: Thomas Darling, MD, PhD
Speakers: Elizabeth Gosnell, DMD, MS, Deeti Pithadia, MD

This lecture will address skin and dental manifestations of TSC and how to treat them, and include strategies for treating those with intellectual disabilities.

Medical and School Records, Organizing Documents, EMR, *Spruce 2*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Reiko Donato, Jessica Krefting, BSN, RN

Managing care for someone with TSC often means keeping track of medical records, school documents, evaluations, IEPs, and test results—which can quickly become overwhelming. This practical discussion session will help families learn how to organize, store, and access important information to better coordinate care and advocate for services.

Saturday (cont.)

4:30 p.m. – 4:45 p.m.	BREAK
4:45 p.m. - 5:30 p.m.	End of Day Q&A and Closing Remarks, *Adams A* Moderator: Steven L. Roberds, PhD Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.
6:30 p.m. - 10:00 p.m.	Blue Night: Closing Dinner honoring Steve and Mary Roberds, *Adams BCD* Emcees: Jim O'Heir and Kari Luther Rosbeck Sponsored by: Joy and Chris Dinsdale Entertainment Sponsor: TSC Alliance Staff Be sure to wear blue for the Blue Night Dinner as we close out the Conference! During dinner, we will recognize TSC Alliance Chief Scientific Officer Steven L. Roberds, PhD, and his wife Mary Roberds for their incredible contributions to the TSC Alliance.

Sunday, August 2, 2026:

Depart: DEN – MCI; Depart DEN 6:10 AM; Flight WN1584

Conference Session Content

Session Types

Keynote/General Sessions (recorded) will feature 3-4 speakers with a moderator and include formal presentations on topics that impact individuals across the lifespan with some time at the end for Q&A.

Panel Presentations (recorded) will feature 3-4 speakers with a moderator who will ask questions to engage interactive conversation amongst the panel and the attendees.

Workshops (non-recorded) are interactive working groups featuring 3-4 speakers, a moderator, and a key take-away learning objective with supporting materials.

Specialty Topic Lectures (recorded) will feature 2+ speakers with a moderator to focus on specialty topics that affect the TSC community.

Discussion Groups (non-recorded) will feature 2-3 speakers and a moderator to discuss more personal topics that affect the TSC community in a closed setting.

End of Day Q&A Sessions, Adams A
The 2026 TSC World Conference includes two end-of-day Question and Answer Sessions. These sessions feature TSC experts who are available for general discussion and questions on any topics related to TSC.

- Friday, July 31: 4:45 to 5:30 p.m.
  Moderator: Shafali Jeste, MD
  Panelists: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

- Saturday, August 1: 4:45 to 5:30 p.m.
  Moderator: Steve Roberds, PhD
  Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD



2026 TSC WORLD CONFERENCE

Agenda and Session Descriptions

Wednesday
July 29, 2026

12:00 p.m. - 6:00 p.m.	Conference Registration, *Cottonwood Foyer*

Thursday
July 30, 2026

7:00 a.m. - 3:00 p.m.	Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 6:00 p.m.	Conference Registration, *Cottonwood Foyer*
12:00 p.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC Research Room, *Spruce 1*
1:00 p.m. - 2:30 p.m.	OPENING KEYNOTE: The State of TSC Around the World, *Adams A* Moderator: Pradnya Gadgil, MBBS, MRCPCH Community Speaker: Jennifer Flinn, EdD Speakers: Kevin Ess, MD, PhD, Anna Jansen, MD, PhD, Kari Luther Rosbeck Sponsored by: Filana Therapeutics, Inc. Kick off the conference with an inspiring keynote that takes you on a journey across continents, offering a dynamic, big-picture view of tuberous sclerosis complex (TSC) research and care worldwide.
2:30 p.m. - 2:45 p.m.	BREAK
2:45 p.m. - 4:15 p.m.	FIRST BREAKOUT SESSION Seizure Treatments, *Adams A* Moderator: Priya Tatachar, MD Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Peter Crino, MD, PhD, Rod Foroozan, MD, Thomas Foutz, MD, PhD, Darcy Krueger, MD, PhD Sponsored by: Filana Therapeutics, Inc., LivaNova, and Montara Therapeutics This session will address seizure treatments available across all ages, as well as discussion about updated guidelines for the use of vigabatrin.

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Federal Assistance Programs and Special Needs Trusts, *Maple 3*
Moderator: Tammy Thorne
Speakers: Deanna Eble, Esq., Lainey Goodwill, JD, Mary McDirmid, ChSNC, ChFC
Sponsored by: MassMutual Special*Care*

This panel session will discuss the transition from childhood to adulthood and the services and supports needed for dependent adults, including their future financial and daily living needs and the timelines and common issues around these processes. The session includes perspectives from US based financial and legal experts, as well as TSC community members.

TSC 101 for Ages 8-17, *Spruce 3-4*
Moderator: Mikenna McFadden
Speakers: Emily Docktor, LMSW, Jennifer Glass, LGC
Sponsored by: Chemistry Rx

Through age-appropriate discussion and interactive activities, this workshop will help children and teens living with TSC and their siblings understand what TSC is and learn how it affects the body, brain, and daily life.

Treatment Options and Clinical Trials in LAM, *Maple 4*
Moderator: Joel Moss, MD, PhD
Community Speaker: Gwen Pryor
Speakers: Greg Downey, MD, FRCPC, Elizabeth (Lisa) Henske, MD, Simon Johnson, DM, FCRP
Sponsored by: Praxis Precision Medicines

This session addresses the link between TSC and lymphangioleiomyomatosis (LAM). Learn about treatment options, available clinical trials, and resources and support available for those with LAM.

Sexual Development for Dependent and Semi-Independent TSC Adults, *Maple 5*
Moderator: Fábio Nascimento, MD
Speakers: Agnies van Eeghen, MD, PhD

This session will explore the important but often overlooked topic of sexual development in individuals with TSC who are dependent or semi-independent. As individuals with TSC move into adolescence and adulthood, they experience the same physical and emotional changes as their peers but may face unique challenges when it comes to communication, boundaries, education, and safety.

Men's Health Issues for Adults with TSC, *Spruce 2*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Mark Keezer, MDCM, PhD, Joshua Samuels, MD, MPH

As men with TSC move through adulthood, they may face specific health concerns that are often overlooked. This session focuses on the unique medical, neurological, and psychosocial aspects of living with TSC as an adult male.

4:15 p.m. – 4:30 p.m. BREAK

2026 TSC WORLD CONFERENCE

Thursday (cont.)

4:30 p.m. - 6:00 p.m. MEET AND GREET OPPORTUNITIES

Adults with TSC (ages 28+), *Spruce 2*
Hosted by: Kate Crossett and Seth Fritts
This casual, peer-focused gathering is an opportunity for adults with TSC (age 28 and up) to connect, share experiences, and build community in a relaxed setting. Whether you're attending your first conference or you're a long-time participant, this space is designed to foster conversation, support, and friendship among adults who understand the TSC journey firsthand.
Sponsored by: Beacon Biosignals and Ovid Therapeutics

Young Adults with TSC (ages 17-27), *Spruce 2*
Hosted by: Kylee Lovato
This casual meet-up is a space just for young adults with TSC to connect, share stories, and get to know others navigating similar experiences. Whether you're in school, working, living independently, or still figuring things out—this is a chance to meet peers who understand life with TSC.
Sponsored by: The Family of Keith Hall

Teens and Young Adults with TSC (ages 13-16), *Adams BCD*
Hosted by: Gayle Saunders
This relaxed and fun meet-up is just for teens with TSC to hang out, connect, and get to know others their age who share similar experiences. Whether you're new to the TSC community or have been coming to conferences for years, this is a great chance to make friends, share stories, and feel supported.
Sponsored by: SK Life Science

Parents of Dependent and Semi-Independent Adults with TSC, *Vail*
Hosted by: Dana Holinka
Connect with other parents and caregivers who understand the unique challenges of supporting an adult with TSC. This informal meet-and-greet offers a welcoming space to share experiences, exchange tips, and build a sense of community with others navigating similar journeys—whether your loved one lives at home, with support, or semi-independently.

Parents of Independent Adults with TSC, *Adams BCD*
Hosted by: Denise Lovato
This relaxed meet-and-greet provides an opportunity for parents and caregivers of independent adults with TSC to connect, share successes, challenges, and practical advice. Whether your adult child is living on their own, working, or pursuing their goals, this session offers a supportive space to exchange experiences and build community with others on similar paths.

Parents/Caregivers of Transition-Age Young Adults, *Maple 5*
Hosted by: Shelly Meitzler
This informal meet-and-greet offers parents and caregivers a welcoming space to connect with others who are navigating the transition from adolescence to adulthood, which brings new challenges and opportunities for young adults with TSC and their families. Share experiences, exchange resources, and gain support from a community that understands these unique needs.
Sponsored by: Stanford Medicine Children's Health

Parents of Young Children with TSC (ages 0-13), *Maple 3*
Hosted by: Heather Atkinson
This casual meet-and-greet is a welcoming space for parents and caregivers of young children with TSC to connect, share stories, and support one another. Whether your child is newly diagnosed or you have been managing TSC for years, this is a chance to build community, exchange practical advice, and find comfort in knowing you're not alone on this journey.
Sponsored by: The TAND Clinic at Le Bonheur Children's Hospital and Total Care RX

Grandparents, *Adams BCD*
Hosted by: Mary Ann Lamb and Marilyn Pruce
This relaxed meet-and-greet provides a welcoming space for grandparents to connect, share experiences, and offer support to one another.

Adult and Young Adult Siblings, *Adams BCD*
Hosted by: Riley Grandia and Mikenna McFadden
This casual meet-and-greet offers adult siblings a supportive space to connect, share experiences, and discuss the unique joys and challenges of having a sibling with TSC. Whether you're navigating caregiving roles, family dynamics, or your own personal journey, this session provides an opportunity to build community with others who truly understand.

4:30 p.m. - 6:00 p.m. TSC Clinic Healthcare Providers' Meeting, *Maple 4*
By invitation only.

6:30 p.m. - 8:30 p.m. Opening Dinner, *Adams BCD*
Moderator: Kari Luther Rosbeck
Speakers: Kevin Ess, MD, PhD, Brittany Smith, Chair, TSC Alliance Board of Directors, Pooja Takhar, PhD, Interim Co-Chair, TSCi
Keynote Address: Greg Grunberg
Sponsored by: UCB, Inc.

The official welcome to the 2026 TSC World Conference! The dinner presentation will include opening remarks on conference format and the importance of building connections within the global TSC community. A keynote address will be given by Greg Grunberg on Caregiver Mental Health followed by a tribute to Katie Smith, Director of Government and Global Affairs, on her 20th anniversary at the TSC Alliance and presentation of the Manuel R. Gomez Award.

2026 TSC WORLD CONFERENCE

Friday,

July 31, 2026

Arrive: MCI – DEN; Arrive DEN 3:55 pm; Flight number WN1563

7:00 a.m. - 8:30 a.m.	Breakfast, *Adams BCD* Sponsored by: TSC Alliance Endowment Fund
7:00 a.m. – 3:00 p.m.	Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
8:00 a.m. - 5:00 p.m.	Conference Registration, *Cottonwood Foyer*
8:30 a.m. - 12:00 p.m.	Sibling Workshop (ages 7-12), *Summit 1* Moderator: Elizabeth Skufca Speakers: Abby Turnwald, MS, CGC This engaging, age-appropriate workshop is designed especially for siblings of individuals with TSC. Through a mix of fun activities, games, and guided discussions, children will have the opportunity to connect with peers who share similar experiences in a supportive and welcoming environment. Led by experienced facilitators, the workshop helps participants better understand TSC in a way that makes sense for their age, while also creating space to express feelings, ask questions, and build confidence. Kids will explore topics like family roles, emotions, and ways to support their sibling—all while making new friends and having fun. This is a great opportunity for siblings to feel seen, heard, and supported as an important part of the TSC community.
8:30 a.m. - 10:00 a.m.	KEYNOTE SESSION: TSC Community-Driven Research and Global TAND Collaborations, *Adams A* Moderator: Steven L. Roberds, PhD Community Speaker: Anita Bhatia, MHA Speakers: Dean Aguiar, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Agnies van Eeghen, MD, PhD Sponsored by: TSC Alliance Board and Endowment Fund Board Members This session will showcase the powerful impact achieved through international collaborations, including Anya's Accelerator and the TANDem project, highlighting how research aims to improve the quality of life for people with TSC-Associated Neuropsychiatric Disorders (TAND).
10:30 a.m. - 12:00 p.m.	SECOND BREAKOUT SESSION Dysregulated Behaviors, *Adams A* Moderator: Tanjala Gipson, MD Community Speaker: Sean Shillinger Speakers: Jamie Capal, MD, Peter Davis, MD This session will explore the types and causes of dysregulated behaviors experienced by individuals with TSC from childhood through adulthood. Dysregulated behaviors (i.e., emotional outbursts, aggression, self-injury, difficulty managing frustration/anxiety) are common challenges in TSC. The session will also discuss how behavioral expression may change over time, providing insights into effective support strategies across the lifespan.

Friday (cont.)

Reproductive Decision Making and Childbearing Considerations, *Maple 3*
Moderator: Heather Radtke, MS, CGC
Community Speaker: Iris Mustich, MPH
Speakers: Lara Friel, MD, PhD, Jennifer Glass, LGC, Lyndsay Harshman, MD, MS
Sponsored by: Jack and Danielle Clark

This session will discuss TSC genetics as it relates to relationships, including potential reproductive challenges and considerations. Maternal fetal medicine experts will cover how to navigate reproductive and perinatal health decisions through postpartum, current gaps in consensus guidelines for care, diagnosing TSC in utero and what's on the horizon.

Accessing Early Childhood Services and Non-Medical Therapies, *Spruce 3-4*
Moderator: Shelly Meitzler
Speakers: Joanna Lomas-Mevers, PhD, BCBA-D, Claire Sartwell, BSN, RN

This workshop will discuss the importance of accessing early intervention and preschool services in the United States. This will include discussion of non-medical therapies: physical therapy, occupational therapy, and speech and language therapy.

SEGA Management Over the Lifespan, *Maple 4*
Moderator: Brenda Porter, MD, PhD
Speakers: Asim Choudhri, MD, Daniel Curry, MD, Pradnya Gadgil, MBBS, MRCPCH, Elizabeth Thiele, MD, PhD

In this session, we'll explore how subependymal giant cell astrocytoma (SEGA) management changes over time, including when treatment is needed, how mTOR inhibitors are used, when surgery might be considered, and how monitoring recommendations shift with age.

Transition into Adulthood for Semi-Independent and Dependent Adults: Living Centers and Employment Options, *Maple 5*
Moderator: Mary McDirmid, ChSNC, ChFC
Speakers: Lisa Szilagyi, Deanna Wall, MHA
Sponsored by: Filana Therapeutics, Inc. and MassMutual Special*Care*

This session will provide insights and resources regarding housing and employment options in the United States that incorporate inclusion in the community based on the unique needs of each individual.

Organizing Your Thoughts and Emotions and Managing Relationships (Only open to adults with TSC), *Spruce 2*
Moderator: Shannon and Rob Grandia
Community Speaker: Danielle Clark, MPH, RS, RD, LD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD
Sponsored by: Jack and Danielle Clark

This session features TSC Alliance Regional Adult Support and Resource Leads, guided by clinical expertise, discussing personal and professional experiences related to managing thoughts, emotions and relationships for adults impacted by TSC. The session will also provide insights and resources on executive functioning and tools to help navigate conversations and relationships.

2026 TSC WORLD CONFERENCE

Friday (cont.)

12:00 p.m. - 1:00 p.m. Lunch, *Adams BCD*
Sponsored by: TSC Alliance Endowment Fund
Optional: Meet the TSC Alliance Board, *Adams, BCD*
Grab your lunch and meet TSC Alliance Board members at designated tables in the lunchroom. Ask questions, hear personal perspectives, and learn more about the TSC Alliance, the role of the Board, and how board members help guide the organization's mission and impact.
Sponsored by: Stewart Smith, and Janice and Julian Gangolli Family

1:00 p.m. - 2:30 p.m. THIRD BREAKOUT SESSION

Sibling Panel and Discussion (ages 13+), Adams BCD
Speakers: Abby Turnwald, MS, CGC, Mikenna McFadden, Aria Moss

Being a sibling to someone with medical and behavioral needs isn't always easy. If you're 13+, join other TSC siblings for a panel and honest conversation about the challenges, concerns, and experiences that come with the role.

Kidney Tumors, Cysts, and Treatment Options, *Adams A*
Moderator: Chris Kingswood, MD
Speakers: John Bissler, MD, Lyndsay Harshman, MD, MS, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This lecture will focus on kidney issues (i.e., renal angiomyolipomas, cysts, function) and treatment options across all ages.

Mood, Anxiety, and Overactive/Impulsive Behaviors, *Maple 3*
Moderator: Anna Jansen, MD, PhD
Speakers: Jamie Capal, MD, Alice Bryn Salter, MD, Agnies van Eeghen, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This panel will discuss attention deficit hyperactivity disorder (ADHD), anxiety, autism, and the breakthrough research being conducted to better understand how they specifically affect individuals with TSC.

Seizure Action Plans and Rescue Medications, *Spruce 3-4*
Moderator: Vijay Vishwanath, MD, PhD
Speakers: Esteban G., Rob Moss, Raj Rajaraman, MD, MS, Irfan Sheikh, MD
Sponsored by: Neurelis, Inc.

In this workshop, you will hear about the importance of creating a Seizure Action Plan, including the use of rescue medications and how to manage emergencies. Additionally, the session will cover how to communicate the content of a Seizure Action Plan to educational accommodation teams and caregivers, as well as in the workplace. You will leave this session with the start of an actionable plan.

Fetal and Perinatal Health, *Maple 4*
Moderator: Heather Radtke, MS, CGC
Speakers: Allison Divanovic, MD, Stephanie Randle, MD, MS, David Ritter, MD, PhD, Sarah Weatherspoon, MD

TSC can sometimes be detected before birth or in the early newborn period, offering families a unique opportunity to prepare for medical care and support early development. This session will explore the latest knowledge and approaches related to fetal and perinatal health in TSC.

Friday (cont.)

Pre-Puberty and TAND, *Maple 5*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Peter Davis, MD, Shafali Jeste, MD, Joanna Lomas-Mevers, PhD, BCBA-D,
Sponsored by: Biogen

This panel will discuss the transition into puberty and early teenage years which often bring changes in TSC-Associated Neuropsychiatric Disorders (TAND), including heightened anxiety, mood swings, behavioral challenges, attention difficulties, and social struggles.

Preparing Your Family for Epilepsy Surgical Evaluation and Surgery, *Spruce 2*
Moderator: Brenda Porter, MD, PhD
Community Speaker: Lesley Holmes, JD
Speakers: Emilie Hyde, S. Katie Ihnen, MD, PhD, Monika Jones, JD

This discussion offers families a unique and personal perspective on preparing for epilepsy surgical evaluation and surgery led by individuals and caregivers who have firsthand experience with the process.

2:30 p.m. – 3:00 p.m. BREAK

3:00 p.m. - 4:30 p.m. FOURTH BREAKOUT SESSION

Epilepsy Surgery and Brain Imaging, *Adams A*
Moderator: Stephanie Randle, MD, MS
Speakers: Jeffrey Blount, MD, MPH, Dan Curry, MD, Aria Fallah, MD, MS, Jonathan Roth, MD, Wenbo Zhang, MD

Join a panel of epileptologists, neurologists and radiologists as they discuss the vital role of brain imaging in the evaluation and planning of epilepsy surgery for individuals with TSC. Panelists will share insights into various imaging techniques, how these tools guide surgical decisions, and what families can expect throughout the process.

Autism: Diagnosis, Therapy and Managing Behaviors, *Maple 3*
Moderator: Peter Davis, MD, PhD
Speakers: Petrus de Vries, MBChB, FRCPsych, PhD, Shafali Jeste, MD, Nicole McDonald, PhD, Mustafa Sahin, MD, PhD
Sponsored by: GondolaBio

Autism spectrum disorder (ASD) is common in individuals with TSC. ASD often presents with a wide range of developmental, communication, and behavioral challenges. This panel brings together clinicians to share diverse perspectives on the diagnosis and management of autism in the context of TSC.

Advocacy and Navigating Education System (Children and Transition-Age), *Spruce 3-4*
Moderator: Elizabeth Skufca
Speakers: Jennifer Flinn, EdD, Lainey Goodwill, JD, Billy Holcombe, PhD, Shelly Meitzler

This workshop session will provide an understanding of an Individualized Education Program (IEP) or 504 plans, goals, progress, and transitions. The session provides tools and insight into the importance of advocating for your child's education at any level. This session will primarily be focused on the North American Educational System.

Managing Progressive Kidney Disease, *Maple 4*
Moderator: Oded Volovelsky, MD, PhD
Speakers: John Bissler, MD, Elahna Paul, MD, PhD, Joshua Samuels, MD, MPH

This session will focus on progressive kidney disease in individuals affected by TSC and the treatment options available to protect kidney function over time.

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Friday (cont.)

Living with LAM, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Cori Fratelli, MSN, FNP-C, RN, Nishant Gupta, MD, Joel Moss, MD, PhD
Sponsored by: Adolfo Orive and Sabine Yazbeck

This session addresses oxygen therapy, rehabilitation, and other respiratory therapies that can be used to improve quality of life for those living with lymphangioleiomyomatosis (LAM).

Navigating Issues Living with TSC as an Independent Adult (TAND, Epilepsy, Surveillance), *Spruce 2*
Moderator: Derek Bauer, MD
Speakers: Jamie Capal, MD, David Ritter, MD, PhD
Sponsored by: Jack and Danielle Clark and Lundbeck US

This session will explore the challenges independent adults with TSC may face, including TAND, epilepsy, and ongoing surveillance of TSC throughout adulthood.

4:30 p.m. – 4:45 p.m. BREAK

4:45 p.m. - 5:30 p.m. End of Day Q&A, *Adams A*
Moderator: Shafali Jeste, MD
Speakers: John Bissler, MD, Jamie Capal, MD, Daniel Curry, MD, Nishant Gupta, MD, Anna Jansen, MD, PhD, Brenda Porter, MD, PhD, David Ritter, MD, PhD

This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.



Saturday
August 1, 2026

7:00 a.m. - 8:30 a.m.	Breakfast, *Adams BCD*
7:00 a.m. – 3:00 p.m.	Research Room Open and Biosample Repository Blood Draw Available, *Spruce 1*
8:00 a.m. - 4:00 p.m.	Conference Registration, *Cottonwood Foyer*
8:00 a.m. - 5:00 p.m.	Exhibit Hall, *Adams Pre-function* Exhibit Hall Sponsor: Upsher-Smith Laboratories, LLC
8:30 a.m. - 10:00 a.m.	KEYNOTE SESSION: Empowering the TSC Community: Research, Treatment, and What Comes Next, *Adams A* Moderator: Raj Rajaraman, MD, MS Community Speaker: Bailey Green Speakers: E. Martina Bebin, MD, MPA, Sergiusz Jóźwiak, MD, PhD, Darcy Krueger, MD, PhD, Lisa Moore-Ramdin, MBBS, MRCPCH, DPM, FFPM, Elizabeth Thiele, MD, PhD Sponsored by: Lundbeck US and Judy and Mark Schaengold The impact of TSC research is realized through improved clinical care and better outcomes for individuals living with TSC. This keynote session will explore the essential role of the TSC community in shaping and conducting clinical trials that lead to new treatments and enhanced quality of life. Attendees will gain insights into the clinical trial process, including how to evaluate risk versus benefit, what it means when a trial does not meet its expected endpoints, and learn about upcoming studies on the horizon.
10:00 a.m. – 10:30 a.m.	BREAK
10:30 a.m. - 12:00 p.m.	FIFTH BREAKOUT SESSION Future Role of Genetics in Personalized Medicine, *Adams A* Moderator: Hope Northrup, MD Speakers: Jeffrey Calhoun, PhD, Laura Farach, MD, Angela Peron, MD, PhD Sponsored by: Ray Chan This session explores how advances in genetic research are paving the way for more personalized, effective therapies and clinical care. Being Proactive with Lifelong Health: Aging and Effects on Brain Health, *Maple 3* Moderator: Thomas Foutz, MD, PhD Speakers: Peter Crino, MD, PhD, Andy Liu, MD, MS, Irfan Sheikh, MD This panel session will provide an overview of changes that can occur as one ages and what can be done to preserve health throughout the lifetime, particularly in regards to brain health.

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Saturday (cont.)

Behavioral Plans, *Spruce 3-4*
Moderator: Kim Hindery
Speakers: Kristn Currans, PsyD, Billy Holcombe, PhD, Joanna Lomas-Mevers, PhD, BCBA-D
Sponsored by: Family of Parker Beebe

This hands-on workshop will guide families and caregivers through the process of developing personalized behavioral plans to address behavior challenges found in TSC.

Other Organ Involvement Through the Lifespan: Heart, Eyes, Liver, and Pancreas, *Maple 4*
Moderator: Kate Richardson, MS, CGC
Speakers: Rod Foroozan, MD, David Ritter, MD, PhD, David Rodriguez-Buritica, MD

This session will discuss tumors associated with TSC, including liver and retinal hamartomas, pancreatic neuroendocrine tumors, and non-malignant tumors in the heart. The panelists will also provide general recommendations on monitoring these organs and treating tumors.

Sleep, *Maple 5*
Moderator: Zacil Vilchis, MD, MSc
Speakers: Stacey Bissell, PhD, Jonathan Lipton, MD, PhD, Donald Phillips, MD, MPH, FACNS
Sponsored by: PsychoGenics Inc.

This discussion will cover sleep difficulties that are common among individuals with TSC and can significantly impact the quality of life for both the individual and their family. This session will offer insights, strategies, and support to improve sleep health.

Caregiver Resources: Self and Respite Care, *Spruce 2*
Moderator: Chris Kingswood, MD
Speakers: Gil Amit, MA, Lilian Ansari, Liezl Schlebusch, PhD

This session will address resources and strategies for managing the stress TSC can bring to a caregiver's life, including tactics for improving your physical and mental health, small steps of self-care for daily life, and information on accessing respite care.

12:00 p.m. - 1:00 p.m. Lunch, *Adams BC*
Sponsored by: Friends of Eric Parkes
Optional: Volunteer Connections & Leadership Opportunities, *Adams D*
Grab your lunch and stop by to connect with volunteer leaders, event hosts and community advocates from across the United States. Hear personal stories, explore opportunities in advocacy, awareness, fundraising, and peer support, and discover how your skills and experiences can make a meaningful impact.

1:00 p.m. - 2:30 p.m. SIXTH BREAKOUT SESSION

Genetic Therapies: Hopes and Hurdles, *Adams A*
Moderator: Elizabeth Thiele, MD, PhD
Speakers: Clayton Beard, PhD, Mark Hester, PhD, Julian Martinez-Agosto, MD, PhD, FACMG, Andrew Steinsapir, MBA
Sponsored by: Biogen and Regeneron

This session will explore the possibilities for genetic therapies in TSC and the challenges researchers face to make it a reality.

Saturday (cont.)

SUDEP Risk and Seizure Monitoring Technology, *Maple 3*
Moderator: James Wheless, MD
Speakers: Peter Crino, MD, PhD, Mary Duffy, Bernice Martin Lee, Donald Phillips, MD, MPH, FACNS

This panel discussion will cover the risks that may contribute to sudden unexpected death in epilepsy (SUDEP) and how technology can help mitigate some of the risks. Content Warning: this is a challenging topic that may include an emotional trigger.

Caregiver Wellbeing, *Spruce 3-4*
Moderator: Katie Smith
Speakers: Anna Jansen, MD, PhD, Liezl Schlebusch, PhD
Sponsored by: Keenova Therapeutics

Caregivers of individuals with TSC report both joys and challenges in their caregiving role. Studies have shown that sometimes these challenges can impact caregiver well-being and family quality of life. This session will help give caregivers tools needed deal with the many thoughts and feelings they experience on a daily basis, using Acceptance and Commitment Therapy (ACT).

Navigating Insurance and Specialty Pharmacy, *Maple 4*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Richard Faris, PhD, Jessica Krefting, BSN, RN, Claire Sartwell, BSN, RN
Sponsored by: PANTHERx Rare Pharmacy

Navigating the United States insurance coverage and specialty pharmacy processes can be challenging, especially when managing treatments for TSC. This workshop provides practical guidance on understanding insurance benefits, prior authorizations, copay assistance, and working effectively with specialty pharmacies.

Health Issues for Women with TSC, *Maple 5*
Moderator: Elizabeth (Lisa) Henske, MD
Speakers: Lara Friel, MD, PhD, Mark Keezer, MDCM, PhD, Kate Richardson, MS, CGC
Sponsored by: Jack and Danielle Clark

Women with TSC face unique health concerns throughout adulthood that may be influenced by hormones, reproductive health, and the progression of TSC-related conditions. This session will explore the intersection of TSC and women's health, providing guidance on managing health across all stages of adult life.

Navigating the Education System for a High School Certificate, *Spruce 2*
Moderator: Jennifer Flinn, EdD
Speakers: Lilian Ansari, Kate Crossett, Elizabeth Skufca

Understanding how to navigate the education system in the United States is essential to supporting academic success and long-term goals. This session will focus on how to work with schools to pursue a high school certificate pathway, an important achievement for many students with learning differences.

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Saturday (cont.)

3:00 p.m. - 4:30 p.m. SEVENTH BREAKOUT SESSION

Taking an Active Role in Government Advocacy: State and Federal, *Adams A*
Moderator: Sara Chieffo
Speakers: Morgan Corder, Margaret Cox, Peter Crino, MD, PhD, Allison Hulme, PhD, Mark Vieth, Laura Weidner, JD

The TSC Alliance is proud of the incredible grassroots advocacy program that has been working to ensure United States federal and state funding of research in TSC. This session will cover the many ways different stakeholders advocate for TSC research funding at the federal and state levels, and how you can get involved.

Overview of TAND Medications for Harmful and Disruptive Behaviors, *Maple 3*
Moderator: Mustafa Sahin, MD, PhD
Speakers: Jay Salpekar, MD, FANPA

This session will focus on medication options for behavioral issues that are commonly associated with TSC and TAND.

Transition into Adulthood for Independent Adults: Preparing for Employment and Higher Education, *Spruce 3-4*
Moderator: Jonathan Goldstein
Speakers: Derek Bauer, MD, Iris Mustich, MPH

This session will provide insights and resources for young adults impacted by TSC and their families to approach the challenges of transitions to adulthood. The group will share their personal experiences and key considerations for independent individuals impacted by TSC who are transitioning out of secondary school and into higher education or employment.

Refractory Seizure Management and Tools, *Maple 4*
Moderator: Rohini Coorg, MD
Speakers: Sam Amin, MBCHB, MRCPCH, MSc, PhD, Rob Moss, Irfan Sheikh, MD, James Wheless, MD
Sponsored by: Aeovian Pharmaceuticals, GRIN Therapeutics, LivaNova, and Lundbeck US

Epilepsy in TSC can often be resistant to medication (refractory). Seizures may not be controlled with initial therapies, resulting in the need to be aware of all possible therapeutic options to treat seizures in a person with TSC. This session will explore other treatment options neurologists may discuss with families and individuals with TSC of any age to try to bring seizures under control.

Skin and Dental Manifestations and Treatment Options, *Maple 5*
Moderator: Thomas Darling, MD, PhD
Speakers: Elizabeth Gosnell, DMD, MS, Deeti Pithadia, MD

This lecture will address skin and dental manifestations of TSC and how to treat them, and include strategies for treating those with intellectual disabilities.

Medical and School Records, Organizing Documents, EMR, *Spruce 2*
Moderator: Wynne Bird, BSN, RN, CPN
Speakers: Reiko Donato, Jessica Krefting, BSN, RN

Managing care for someone with TSC often means keeping track of medical records, school documents, evaluations, IEPs, and test results—which can quickly become overwhelming. This practical discussion session will help families learn how to organize, store, and access important information to better coordinate care and advocate for services.

Saturday (cont.)

4:30 p.m. – 4:45 p.m.	BREAK
4:45 p.m. - 5:30 p.m.	End of Day Q&A and Closing Remarks, *Adams A* Moderator: Steven L. Roberds, PhD Panelists: Peter Crino, MD, PhD, Thomas Darling, MD, PhD, Petrus de Vries, MBChB, FRCPsych, PhD, Elizabeth (Lisa) Henske, MD, Mark Hester, PhD, Angela Peron, MD, PhD, Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD This session will feature TSC expert speakers from sessions throughout the day who will be available for general discussion and questions on any topics related to TSC.
6:30 p.m. - 10:00 p.m.	Blue Night: Closing Dinner honoring Steve and Mary Roberds, *Adams BCD* Emcees: Jim O'Heir and Kari Luther Rosbeck Sponsored by: Joy and Chris Dinsdale Entertainment Sponsor: TSC Alliance Staff Be sure to wear blue for the Blue Night Dinner as we close out the Conference! During dinner, we will recognize TSC Alliance Chief Scientific Officer Steven L. Roberds, PhD, and his wife Mary Roberds for their incredible contributions to the TSC Alliance.

Sunday, August 2, 2026:

Depart: DEN – MCI; Depart DEN 6:10 AM; Flight WN1584