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- Promote awareness of your company.
- Support the next generation of TSC research breakthroughs.

For More Information:

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2023 International TSC Research Conference Overview

The 2023 International TSC Research Conference takes place September 7-9, 2023, at the Omni Shoreham Hotel in Washington, DC. This three-day conference will bring together basic and clinical researchers interested in tuberous sclerosis complex (TSC) and related disorders, including epilepsy, autism, cancer, and rare diseases with similar features. This is important because research into TSC also increases knowledge in the broader fields of autism, epilepsy, and cancer, which can improve the understanding and treatment of TSC. Through communication and collaboration of participating senior and junior researchers and trainees, the conference will stimulate and accelerate basic and clinical research to improve health care and quality of life for individuals with TSC and potentially many other related disorders.

These goals are important and timely because:

- Neurological (e.g., epilepsy) and psychiatric issues have a severe impact on quality of life in individuals with TSC and related diseases, yet treatment fails in many cases because the underlying relationship of phenotype to neuropathology and genetics is poorly understood.
- Although the mTOR inhibitors sirolimus and everolimus have been approved by the FDA for treatment of LAM, focal-onset seizures, and specific brain, renal, and skin tumors associated with TSC, mTOR inhibition only shrinks and stabilizes LAM progression and tumor growth. Tumors will grow again if drug treatment is stopped, so a need for more long-lasting and more tolerable treatments exists.
- Clinical trials to find ways to better treat or prevent epilepsy, neuropsychiatric disorders, and tumor growth require international collaborations to achieve adequate statistical power in a rare disease whose phenotype varies from person-to-person.

The conference will achieve its goals through:

- Sponsoring a half-day TSC Early Career Researcher Symposium on September 7 before the main conference begins.
- Bringing trainees and junior faculty selected from submitted abstracts to the Early Career Researcher Symposium and research conference to: (a) engage with other trainees and early-stage investigators regarding issues unique to their career stage, (b) share their data in platform and poster presentations with feedback on their science and on their presentation skills, and (c) expose them to broader research opportunities (e.g., industry, patient advocacy) in the field of TSC and related disorders.
- Increasing diversity of attendees by reserving half of the travel awards for scientists who belong to underrepresented groups in research, including scientists without data to present on TSC-related work.
- Assembling non-TSC-focused researchers together with TSC experts in an environment conducive to sharing data, networking, and building opportunities for future collaboration.
- Platform sessions designed specifically to facilitate cross-specialty understanding by combining in the same session—to the extent reasonably possible—basic, translational, and clinical research data.

About Tuberous Sclerosis Complex (TSC)

Tuberous sclerosis complex (TSC) is a genetic disease that causes non-malignant tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. The aspects of TSC that most strongly impact quality of life are generally associated with the brain: seizures, developmental delay, intellectual disability and autism. Approximately 85 percent of individuals experience seizures during their lifetime, and about one-third of these manifest as infantile spasms, a devastating form of epilepsy occurring in early childhood. Autism occurs in approximately 50 percent of individuals with TSC, and other behavioral and psychiatric symptoms—such as aggression and anxiety—are common.

The incidence and severity of the various aspects of TSC can vary widely between individuals, even between identical twins. At least two children born each day will have TSC. Current estimates place tuberous sclerosis complex-affected births at one in 6,000. Nearly 1 million people worldwide are estimated to have TSC, with approximately 50,000 in the United States. Many cases may remain undiagnosed for years or decades due to the relative obscurity of the disease and the mild form symptoms may take in some people.

Because of the wide variety of symptoms associated with this disease, TSC can be considered a “linchpin” disease. Breakthroughs in TSC can lead to breakthroughs in other diseases, including autism, epilepsy and even cancer.



2023 International Tuberous Sclerosis Complex Research Conference Steering Committee

Conference Co-Chairs

- **Rebecca Ihrie, PhD**, Associate Professor Cell & Developmental Biology and Neurological Surgery, Vanderbilt University School of Medicine
- **Shafali Spurling Jeste, MD**, Chief, Division of Neurology, Co-Director, Neurological Institute, Children's Hospital, Los Angeles

Early Career Researcher Symposium Co-Chairs

- **Nicole McDonald, PhD**, Assistant Clinical Professor, UCLA Semel Institute
- **Uchenna John Unachukwu, PhD**, Associate Research Scientist, Columbia University Medical Center

Organizing Committee Members

- **Jamie K. Capal, MD**, Associate Professor of Pediatrics and Neurology, University of North Carolina at Chapel Hill
- **Laura Farach, MD**, Associate Professor, Division of Medical Genetics, Department of Pediatrics, University of Texas Health Science Center at Houston
- **Zoë Fuchs**, Manager, Translational Research, TSC Alliance
- **Gina Lee, PhD**, Assistant Professor, Microbiology & Molecular Genetics, UC Irvine School of Medicine
- **Carmen Priolo, MD, PhD**, Assistant Professor of Medicine, Brigham and Women's Hospital
- **Tracee Ridley-Pryor, DNP PMHNP-BC**, Psychiatric Mental-Health Nurse Practitioner, Le Bonheur Children's Hospital and University of Tennessee Health Science Center
- **Steven L. Roberds, PhD**, Chief Scientific Officer, TSC Alliance
- **Kari Luther Rosbeck**, President & CEO, TSC Alliance
- **Gabrielle Rushing, PhD**, Director, Research, TSC Alliance
- **Katie Smith**, Director, Government & Global Affairs, TSC Alliance
- **Daniel Vogt, PhD**, Assistant Professor, Department of Pediatrics and Human Development, Michigan State University
- **Oded Volovelsky, MD, PhD**, Pediatric Nephrology Unit Head, Hadassah Hebrew University Medical Center
- **Anne Wolfe**, Senior Manager, Strategic Projects, TSC Alliance
- **Jane Yu, PhD**, Professor, Pulmonary, Critical Care and Sleep Medicine, University of Cincinnati

Attendee Profile

The 2023 International TSC Research Conference will draw individuals from around the world. The audience will be composed of basic and clinical science researchers, as well as health professionals who provide care for individuals with TSC. Based on similar conferences in recent years, we anticipate 200-250 attendees, including at least 12 invited speakers, 15 talks selected from submitted abstracts, and approximately 60 posters.

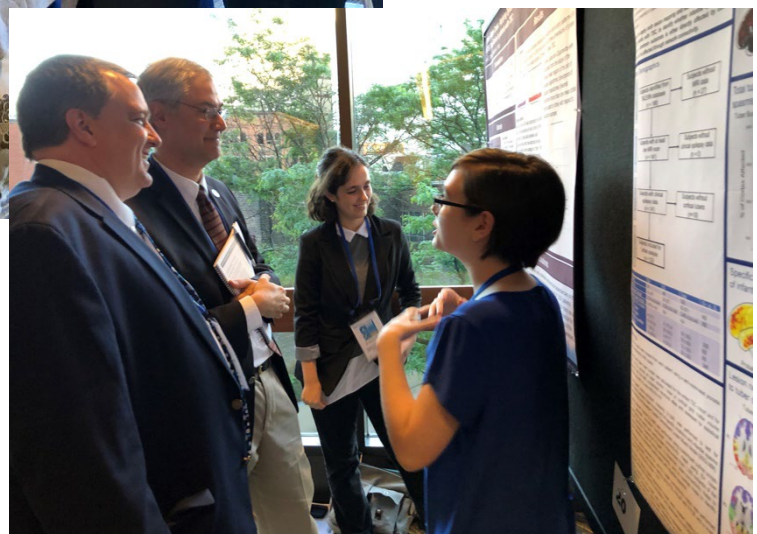
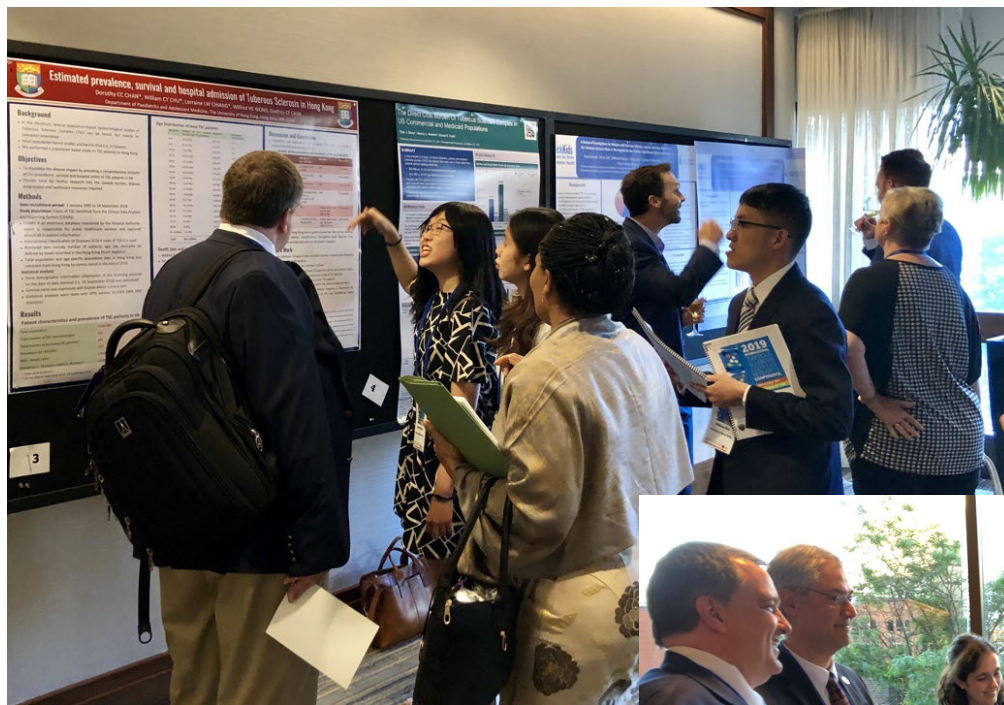
Based on previous International TSC Research Conferences, we anticipate participants of approximately 25 percent non-clinical academic researchers, 35 percent clinical academic researchers and 25 percent scientists from industry, with the remainder being from government agencies, non-profit organizations, or families affected by TSC. The conference is open to anyone who would like to attend.

2023 International TSC Research Conference Agenda

September 7	Early Career Researcher Symposium, Thursday
Morning	<p>Welcome and Introductions (15 min)</p> <ul style="list-style-type: none"> TSC patient or family member Co-chairs outline purpose and goals of the symposium <p>Presentations by early career researchers (60 min)</p> <ul style="list-style-type: none"> Three talks selected from abstracts <ul style="list-style-type: none"> 15 minutes of constructive feedback facilitated by senior scientist moderator <p>Networking break (30 min)</p> <p>Presentations by early career researchers (60 min)</p> <ul style="list-style-type: none"> Three 15-minute talks selected from abstracts <ul style="list-style-type: none"> 15 minutes of constructive feedback facilitated by senior scientist moderator <p>Career development panel – three senior TSC scientists (60 min)</p>
Early Afternoon	Lunch and Networking (60 min)

September 7	Research Conference Day One, Thursday
Mid-Afternoon	<p>Welcome and Plenary Session 1: Chemical and Cell Biology</p> <ul style="list-style-type: none"> TSC patient or family member Ben Philpot, PhD (identification of novel therapeutics for neurodevelopmental disorders) 2 short talks selected from abstracts Break (30 min) TBD (design of novel mTORC1 inhibitors) 4 short talks selected from abstracts
Evening	Dinner and Keynote Speaker: Martina Bebin, MD MPA (outcomes and impact of the PREVeNT (Preventing Epilepsy Using Vigabatrin In Infants With TSC) trial)
September 8	Research Conference Day Two, Friday
Morning	<p>Plenary Session 2: Biomarkers and Ethics in Early Intervention</p> <ul style="list-style-type: none"> TSC patient or family member Connie Kasari, PhD (early intervention in autism) Kate MacDuffie, PhD (ethical and social impacts of advances in neuroscience on children and families impacted by neurodevelopmental disorders) TBD (early antecedents to psychiatric risk) Break (30 min) Panel discussion on ethics of early intervention: Drs. Bebin, Kasari, MacDuffie and Spann (45 min) 2 short talks selected from abstracts
Noon	Lunch provided (1 hr)
Afternoon	<p>Breakout groups (90 min)</p> <ul style="list-style-type: none"> Topics TBD Break (30 min) <p>Plenary Session 3: TAND (TSC-Associated Neuropsychiatric Disorders) and Epilepsy Research</p> <ul style="list-style-type: none"> TANDem Consortium Speaker (TANDem project outcomes and next steps) Howard Weiner, MD (impact of advances in neurosurgery in TSC) 2 short talks selected from abstracts

Early evening	Poster Session and Reception (3 hours)
September 9	Research Conference Day Three, Saturday
Morning	Plenary Session 4: Organoids and Cell Development <ul style="list-style-type: none"> • TSC patient or family member • Manoocher Soleimani, MD (mechanisms of renal cystogenesis) • Jennifer Sucre, MD (early lung development) • 1 short talk selected from abstracts • Break (30 min) • Nina Corsini, PhD (contributions of interneuron progenitor cells to neurological disease) • 4 short talks selected from abstracts
Noon	Lunch provided (1 hr)
Early Afternoon	Report on breakout sessions (30 min) Plenary Session 5: Hot Topics Advancing TSC Research and Clinical Care <ul style="list-style-type: none"> • Isaac Rodriguez-Chavez, PhD MHS (clinical research approaches to increase diversity of research participants) • Additional 45 minutes available
Mid-Afternoon	Joint session (60 min) with individuals and families attending the Regional TSC Conference for patients and families <ul style="list-style-type: none"> • Conference co-chairs moderate a panel discussion and Q&A to convey the relevance and impact of the research conference to scientific and non-scientific attendees alike



About the TSC Alliance

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with tuberous sclerosis complex (TSC). We drive research, increase care quality, improve access, inspire hope and advocate with and for all affected by the disease. The TSC community is our strongest ally. With the power of individuals, families, organizations and more, we can create a future where everyone with TSC can realize their full potential—no matter how complex their journeys are to get there.

The TSC Alliance is a mission-driven organization with a professional staff of 23. The TSC Alliance is governed by a Board of Directors comprised of people affected directly by the disease, such as parents or adults with TSC, as well as business professionals. The staff and board are also supported by an army of more than 2,200 volunteers who all work together to improve the quality of life for every individual and family affected by TSC by focusing on three main pillars:

1. Outreach and Education
2. Advocacy
3. Research

Over the years, the TSC Alliance has funded more than \$33.6 million in support of basic, translational and clinical research. Because of our advocacy for research and promoting young investigators, we funded and cultivated a new generation of senior scientists who today receive generous funding from sources such as the National Institutes of Health and the Department of Defense Congressionally Directed Medical Research Program. Due to the strength of our grassroots volunteers, more than \$550 million has been spent on TSC research over the past 20 years from these important sources.

In our quest to find a cure, funds provided by the TSC Alliance over the last decade have contributed to several significant scientific breakthroughs. TSC Alliance-sponsored research helped support the identification of the two genes that cause TSC, developed a genetic test and initiated the first clinical trials in TSC. Today, because of this very early research and basic science understanding of the disease, there are currently two FDA-approved drugs specifically for TSC. In October 2016, the TSC Alliance-supported Clinical Research Consortium launched the first preventative clinical trial in epilepsy and TSC in the US with an aim to prevent seizures from developing in new-borns with TSC. We anticipate interim results to be presented at this conference.

Now more than ever hope is on the horizon for therapies that will greatly improve the lives for all those with TSC.



Sponsorship Opportunities

The conference provides maximum exposure to showcase products, increase visibility among care providers and leading scientists and partners with the only national health nonprofits serving those affected by TSC. Sponsorship of this conference provides a strategic partnership and accessibility to conference participants.

	Title \$150,000	Presenting \$50,000	Feature \$25,000	Poster Session \$15,000	Advocate \$10,000	Session \$5,000
Promoted as Conference Sponsor	Promoted as Title Sponsor	Promoted as Presenting Sponsor	X	X	X	X
Complimentary Registrations	10	8	6	5	4	2
Exhibit Table	X (Premier Location)	X (Premier Location)	X (Prominent Location)	X	X	X
Acknowledgment in Program Book	Full Page	Full Page	Full Page	Full Page	Half Page	Half Page
Listed in Program Book	X	X	X	X	X	X
Listed in Perspective Magazine	X	X	X	X	X	X
Listed in Conference Materials	X	X	X	X	X	X
Recognition During Conference Opening	X	X	X	X	X	X
Logo on Registration Website	X	X	X	X	X	X
Logo on conference signage and collateral materials	X	X	X	Poster Session Only	Session Only	Session Only
Social Media Mention	X	X	X			
Sponsorship Highlight in Perspective Magazine	X	X				
Opportunity to hold meeting with key opinion leaders	X	X				
Logo included on program book cover	X	X				
Opportunity to host an exclusive Meet and Greet for Medical Professionals in attendance	X					

Additional opportunities are available to underwrite specific activities associated with the conference.

Early Career Research Symposium Sponsor (1 available) \$7,500

- Promoted as Early Career Research Symposium Sponsor with company / individual name included on conference signage and symposium signage
- 2 complimentary registrations
- Exhibit table in Exhibit Hall
- Half page acknowledgement in conference program book
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- Recognition during Early Career Research Symposium
- Logo on website registration

Session Sponsor (6 available) \$5,000

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- Exhibit table in Exhibit Hall
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- Listed in program book
- Recognition during sponsored session
- Logo on website registration

Conference Book Underwriter (1 available) \$5,000

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- 2 complimentary registrations
- Exhibit table in Exhibit Hall
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- Listed in program book
- Logo on website registration

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2023 International TSC Research Conference Sponsorship Commitment Form

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Name as it appears on card: _____

Return this agreement to:

Lisa Moss, Vice President, Donor Relations
TSC Alliance

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Silver Spring, MD 20910

lmoss@tsalliance.org or fax: 301-562-9870

**Hope no matter
how complex**

