

PERSPECTIVE

A MAGAZINE FROM THE TSC ALLIANCE



FALL 2023 • VOLUME 155

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“As we hope you know, everything the TSC Alliance does is laser focused on ensuring everyone touched by TSC has what they need to live their fullest lives.”

As the end of 2023 nears, the TSC Alliance is proud to have experienced another impactful year. This issue of *Perspective* is packed with community accomplishments, new projects, additional support resources and information about ongoing tuberous sclerosis complex (TSC) research. The cover story features Hope Hynes Gallagher, a young girl with TSC, who has faced some significant challenges, yet she’s benefited from our organization’s support programs and ongoing TSC research in meaningful ways.

On page 16, you’ll find a summary of our recent 2023 International TSC Research Conference, which was our first in-person research conference since before the pandemic. It was a resounding success and lays the groundwork for the next stage of identifying new and better treatments and other scientific discoveries. The keynote speaker was Dr. Martina Bebin, highlighting the findings of the PREVeNT Trial, the first preventative trial for epilepsy in the United States. You can read more about the trial’s results on page 22.

Throughout this issue, you’ll also find articles about the TSC Alliance’s efforts to address TSC-associated neuropsychiatric disorders (TAND), perinatal and reproductive health, sudden unexpected death in epilepsy (SUDEP), federal and state TSC funding and more. Our ultimate goal is for TSC to one day become an easily manageable chronic disease.

As we hope you know, everything the TSC Alliance does is laser focused on ensuring everyone touched by TSC has what they need to live their fullest lives. One way we determine those needs is through our Constituent Surveys, which we offer every five years. On page 10, you can read about the top-line results from this year’s survey. Thanks to everyone who participated because your input is invaluable in our planning for the future.

Speaking of the future—2024 marks the 50th anniversary of the TSC Alliance! To celebrate the landmark occasion, we will debut a new website in January, introduce new Vision and Mission Statements, embark on a

new five-year strategic plan (based on your input from the Constituent Survey) and honor the past and future throughout the year with videos, social media campaigns and special events, including Comedy for a Cure[®] and Step Forward to Cure TSC[®]. We’ll finish the celebrations during a 50th Anniversary Gala in New York City on October 25. Everything in 2024 will highlight the organization’s unwavering commitment to holding up the TSC community and paying tribute to all your accomplishments over five decades.



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FALL 2023 • VOLUME 155

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If you have opinions, questions or articles for *Perspective*, we would like to hear from you. Please contact the managing editor to obtain a submissions form and guidelines.

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TSC Alliance launches SUDEP Quality Improvement Initiative

Let's talk about it

Talking about difficult topics—such as Sudden Unexpected Death in Epilepsy (SUDEP)—can be tough for healthcare providers and for individuals/caregivers of those with epilepsy. This year has been specifically hard for many due to the sudden death of loved ones within our TSC community. As we all know, TSC is a complex disease, and often the greatest fears of individuals and caregivers who are navigating this journey are left unspoken.

To help minimize those fears and normalize the difficult conversation surrounding SUDEP, the TSC Alliance held a webinar this past May about SUDEP and processing grief, presented by Peter Crino, MD, PhD, TSC Clinic Director at the University of Maryland Medical Center; Ashley Pounders, MSN, FNP-C, TSC Alliance Director of Medical Affairs; and Shelly Meitzler, our Director of Outreach & Support. This webinar profoundly affected participants with an outpouring of support from the TSC community and healthcare providers to act on this unmet need. You can view the webinar's recording at tscalliance.org/SUDEPwebinar.

SUDEP is defined as “death in a patient with epilepsy that is not due to trauma, drowning, status epilepticus or other known causes but for which there is often evidence of an associated seizure” and is a leading cause of death in patients with epilepsy (Devinsky et al., 2018). Several SUDEP risk factors closely coincide with symptoms seen in people with TSC, such as recurrent convulsive seizures, intellectual disabilities, early onset of seizures, prolonged epilepsy duration, nocturnal seizures, male gender and polytherapy with frequent antiseizure medication changes. (Parthasarathy et al., 2021).

The challenge is the heightened risk of SUDEP faced by people with TSC who have drug-resistant epilepsy, commonly called refractory epilepsy. This subgroup faces a staggering 15-fold higher risk of SUDEP compared to those with well-controlled epilepsy. Approximately 80% of individuals with TSC are affected by epilepsy, and two-thirds will experience refractory epilepsy (Wu, J. Y. et al., 2019).

This elevated SUDEP risk in individuals with TSC underscores the importance of clinicians who treat TSC patients being well-prepared to engage in SUDEP discussions with their patients. As a result, the SUDEP QI (Quality Improvement)

Initiative was launched. The project is being led by Ashley Pounders, MSN, APRN, FNP-C; Iris Mustich, MPH; Tracee Ridley-Pryor, DNP, APRN, PMHNP-BC; Liz Cassidy, MPH; Ayat Abi; and Dana Bridges, MS, RN, CFNP-BC. Our goal is to assess the current landscape of SUDEP communication by healthcare providers and gauge patient/family knowledge of SUDEP, along with their perception of communication with providers. This assessment will serve as a critical foundation for us to develop a tailored framework for enhancing SUDEP education for patients with TSC and the healthcare professionals who serve them.

How you can get involved

As mentioned earlier, the first phase of this initiative is to assess the knowledge of individuals with TSC, families and caregivers as well as the communication practices of healthcare providers regarding SUDEP.

To ease this assessment, we have developed two surveys: one for healthcare providers and another for individuals with TSC, families and caregivers. If you or someone you know is interested in taking part in this survey, please scan the appropriate QR code below. Your input is invaluable in advancing our understanding of SUDEP and improving education and communication in the TSC community. Thank you for your participation. Please note: The survey deadline is Friday, December 29.



Scan for TSC/families/
caregivers.



Scan for healthcare
providers

For more information

For all inquiries related to this initiative, please email biosamples@tscalliance.org.



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2023 Step Forward to Cure TSC® results

This year's Step Forward to Cure TSC® walk series kicked off on April 15 and wrapped up during the weekend of May 20-21. The outstanding success of this year's events can be attributed to the exceptional contributions of the National Planning Committee, Walk Leads and countless devoted volunteers. Their unwavering support was instrumental in organizing and hosting 14 in-person events across the country. This year's Step Forward to Cure TSC featured 3,085 participants, resulting in a remarkable fundraising total of \$786,000.



Walk Leads and Locations

- Cassie Souder: Fisher IN
- Alexandria Ewing and Lauren Perry: Nashville, TN
- Gloria and Lee Triebnbach, Adrienne Wasserman and the local planning committee: Renton, WA
- Andrew Darvin: Orlando, FL
- Kristen Moore and Heather Harden: Rock Hill, SC
- Bridget Rich and Stephanie Ven Beekum: Salt Lake City, UT
- Bridgett Langstaff: Liverpool, NY
- Shannon and Rob Grandia and Frances Harper: Irwindale, CA
- Noor and Zohra Panjwani and the local planning committee: Carrollton, TX
- Jack and Fran Lyons: West Chester, PA
- Alexandra Dahlgren: Kansas City, KS
- Heather Lens: Tulsa, OK
- Nathalie Mortine: Cincinnati, OH
- Lauren Shillinger and Michal Cepler: Rockville, MD

On Sunday, May 21, we held the **Wrap-Up Rally** featuring **Dr. Derek D. Bauer**, who delivered the opening remarks. **Bill Joseph**, Chair of the TSC Alliance Board of Directors, co-hosted the rally alongside **Kari Luther Rosbeck**, President & CEO. Bill acknowledged **Nobelpharma** as our Title Sponsor and **Marinus Pharmaceuticals** as Premier Sponsor and also thanked all our exceptional national and regional sponsors. Their unwavering commitment to this year's event played a crucial role in its success, instilling hope in countless individuals every single day. We would also like to extend a special thank you to **Althea Grace** for her live performance.

National sponsors









TSC Hero sponsor

MassMutual SpecialCare

TSC Warrior sponsors

BridgeBio, MN Epilepsy Group, Ovid Therapeutics, Stanford Medicine Children's Health

TSC Clinics and TSC Centers of Excellence

In a remarkable display of community engagement, we are thrilled so many TSC Clinics and TSC Centers of Excellence once again exceeded expectations. With immense appreciation, we extend our thanks to each for collectively raising more than \$27,800, including: Advent Health Epilepsy Team (Lee, Seo); Ann & Robert H. Lurie Children's Hospital of Chicago (Team Lurie Childrens); Chapel Hill TSC Clinic (Capal); Children's National Medical Center; Children's Hospital Los Angeles (Team CHLA); Children's Hospital of Orange County (Team Choc); Cincinnati TSC Clinic; Kennedy Krieger; Minnesota Epilepsy Group; Orlando Walk Team (Prakash); Seattle Children's; University of Alabama at Birmingham; University of California, Los Angeles; University of Iowa; University of Maryland TSC Center; and Washington University in St. Louis (Wash U Warriors).

Top prize winners

The following totals reflect the amounts at the time of the drawings.

Top teams

- 1st Place: Bodie's Buddies (Kaylan O'Hara, Team Captain): \$20,829
- 2nd Place: Louie Louise (Franny Kuehn, Team Captain): \$18,314
- 3rd Place: Isla's Dream Team (Jenelle Hitchcock, Team Captain): \$13,907

Top TSC Clinics and TSC Centers of Excellence

- 1st Place: Seattle Children: \$13,784
- 2nd Place: (UCLA) University of California, Los Angeles: \$2,845

Largest teams

- Corporate: Nobelpharma (25 team members)
- Non-Corporate: Ethan's Entourage (103 team members)

TSC miles

- Most Miles Walked: Eric Chong and Sophia Cortez
- Top 5K Finisher: Mesa Ackley-Munson (Team Reid)

Grand prize

- Stormy Sunderland, Team Captain (3 Generation TSC)

Save the date!

The **2024 Step Forward to Cure TSC** officially opens registration at StepForwardtoCureTSC.org on January 1, 2024. Get ready for an exciting month-long event, kicking off in mid-April and concluding the weekend of May 18-19, 2024. Registration is free!



22nd Annual Comedy for a Cure

On April 2, the TSC Alliance hosted an incredible night of charity and comedy at the **22nd Annual Comedy for a Cure[®]**, with Jazz Pharmaceuticals as headliner sponsor, **raising almost \$465,000** at the Avalon Hollywood.

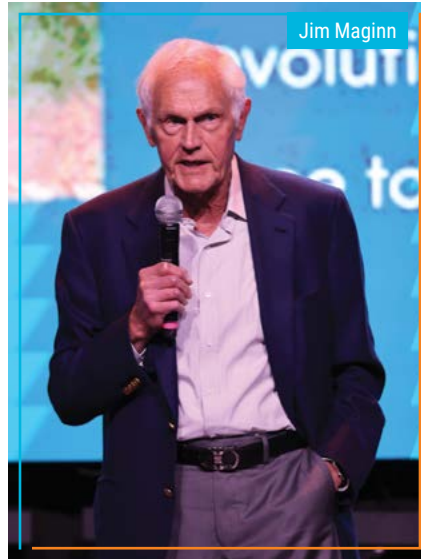
It was our honor to present the **Courage in Leadership Award** to **The Holmes Family**, who have been some of the organization's most dedicated supporters since their daughter Seraphina was diagnosed with TSC. We were also thrilled to honor **The Maginn Family** with the **TSC Champion Award** for more than two decades of innovative investment in TSC research.

This exciting evening was led by Co-Chairs **Anita Bhatia** and **Jill Hyman** and emceed by two talented entertainers from our Comedian Committee, **Mo Collins** and **Wendy Liebman**. We were thrilled to feature the extraordinary talent of Special Guest Star **Alonzo Boddin** and Headliner **Russell Peters** after our auctioneer extraordinaire, **Damon Casatico**, orchestrated a record-breaking Fund a

Special events (continued)

Cure and Live Auction that raised more than \$135,000.

We were thankful to have Jazz Pharmaceuticals as our Headline Sponsor and The Ramesh and Kalpana Bhatia Family Foundation, Kay and Will Cooper, The Maginn Family and Nobelpharma as our Standing Ovation



Sponsors for this special evening. Additional sponsors included Marinus Pharmaceuticals, The Szilagyi Family, Ten Oaks, WNC Inc., BridgeBio, CVS Health, Tim and Kathi Dills, Horizon Therapeutics, MassMutual SpecialCare, Neurelis, Skechers, Upsher-Smith Laboratories LLC, Longboard Pharmaceuticals,

Mallinckrodt Pharmaceuticals, UCB Inc., Ray Chan, Christy Hobart and Henry Shapiro, Ted and Peggy Mastroianni, Richard and Lauren Packard, Edina Kiss and Tom Bercu Presents.

Our next Comedy for a Cure is scheduled for April 14, 2024, at Vibiana in Los Angeles, so mark your calendars now!



New: Team TSC endurance campaigns!

The TSC Alliance is thrilled to introduce our new **Team TSC Endurance**, a new easy-to-use online fundraising platform. This campaign is specifically designed to harness your unrelenting commitment in the fight against tuberous sclerosis complex (TSC), combined with your passion for physical fitness and fundraising.

Jackie Grenia, a dedicated and resilient TSC mom, joined Team TSC Endurance in honor of her daughter,

Evie. Jackie's endurance challenge was a 20-mile hike through the Weldon Spring Conservation area in 7 hours. Through her awe-inspiring hike, she managed to rally support from friends, family and the community, **raising \$1,555.**

Team TSC Endurance allows you to set your own goal, personalize your fundraising page and begin your fundraising right away, regardless of whether you decide to participate



in an already-existing event or take advantage of the chance to organize one yourself. **Register online at give.tscalliance.org/teamtscendurance2023.**

Other community campaigns

We are grateful for the incredible efforts of our TSC Champions for hosting a series of remarkable fundraisers between July and October 2023. It is truly inspiring to witness the unwavering dedication and commitment of our volunteers, who worked tirelessly across the country to make these events a success. Please note: The totals raised in the following information reflect the amounts at the time of publication.

14th Annual Western PA Golf Tournament

Hosted by Jim and Lori Hartge, Scott and Lori Shoup
July 8, 2023 | Raised: \$5,800

2nd Annual Pours 4 Parker B

Hosted by Ryan and Andrea Beebe
July 23, 2023 | Raised: \$16,473



18th Annual Youmans Friends and Family BBQ

Hosted by Bill and Nancy Youmans
September 9, 2023 | Raised: \$6,475

5th Annual Teeing Off Fore TSC!

Hosted by Joseph Cervantez
September 30, 2023 | Raised: \$24,049

Heather Joy Memorial Golf Tournament

Hosted by Christy Buntrock
September 9, 2023 | Raised: \$5,299

Keith Hall Memorial Golf Tournament

Hosted by Nick Giardina, Andrea Hall and Friends
October 10, 2023 | Raised \$7,249

Facebook donations

We deeply appreciate your generous support of the TSC Alliance on your birthday or other special occasions. We are grateful for the generous **\$12,000 and counting** raised on Facebook between December 2022 through September 2023.

Awareness, education, commitment: Nobelpharma America supports the TSC community

When a wise person once said, “There’s strength in numbers,” they might have been describing any group of people involved with a rare disease. A growing, thriving community builds stability, influence and the capacity to help individuals in many ways. Clearly, this is especially important for people diagnosed with a rare disease.

Nobelpharma America is committed to supporting community efforts for people with tuberous sclerosis complex (TSC) and other rare medical conditions. Nobelpharma develops drugs and medical devices for diseases that other pharmaceutical companies may overlook because of the small number of patients affected, or other reasons. As part of that commitment, it is also dedicated to bringing awareness to issues that can affect the TSC community.

Toward that end, Nobelpharma America has proudly sponsored several exciting events this year.

Comedy fundraiser, community walks, regional conferences

For example, Nobelpharma America was a sponsor of the 22nd Annual Comedy for a Cure[®], a popular TSC Alliance fundraiser. The event brought the community together for fun and entertainment while contributing to efforts to find a cure for TSC.

They also helped to bring hundreds of people together in April and May for the Step Forward to Cure TSC[®] Hybrid Walk-Run-Ride. A national fundraiser, this high visibility event took place in 14 areas of the country.



The Maryland-area walk resulted in more than 200 participants bringing in more than \$53,000 for the effort. Nationally overall, family, friends, corporate partners and others walked to raise more than \$786,000 to support TSC medical research being conducted through the TSC Alliance.

Nobelpharma America also participated in all four Regional TSC & LAM Conferences across the U.S. this year. These events provided a forum for the TSC community to exchange information and learn about the disease.

Disease awareness website and educational book

Nobelpharma America also launched FACE FORWARD this year, an educational website focused on education and awareness of facial angiofibroma associated with TSC. FACE FORWARD offers educational content about TSC and facial angiofibroma, an online tool for use helping to locate local treatment centers, stories from people living with facial angiofibroma, and more. Visit faceforwardwithTSC.com for more information.

Another highlight of 2023 was Nobelpharma America’s launch of an educational storybook titled, “Totally Super Cool.” By illustrating different ways children can comfortably open up to others about their disease, this colorful, playfully illustrated book encourages meaningful conversations between caregivers and children who have facial angiofibroma associated with TSC. “Totally Super Cool” is also available digitally on our educational website, FACE FORWARD at faceforwardwithtsc.com.

COVER STORY

A story of Hope

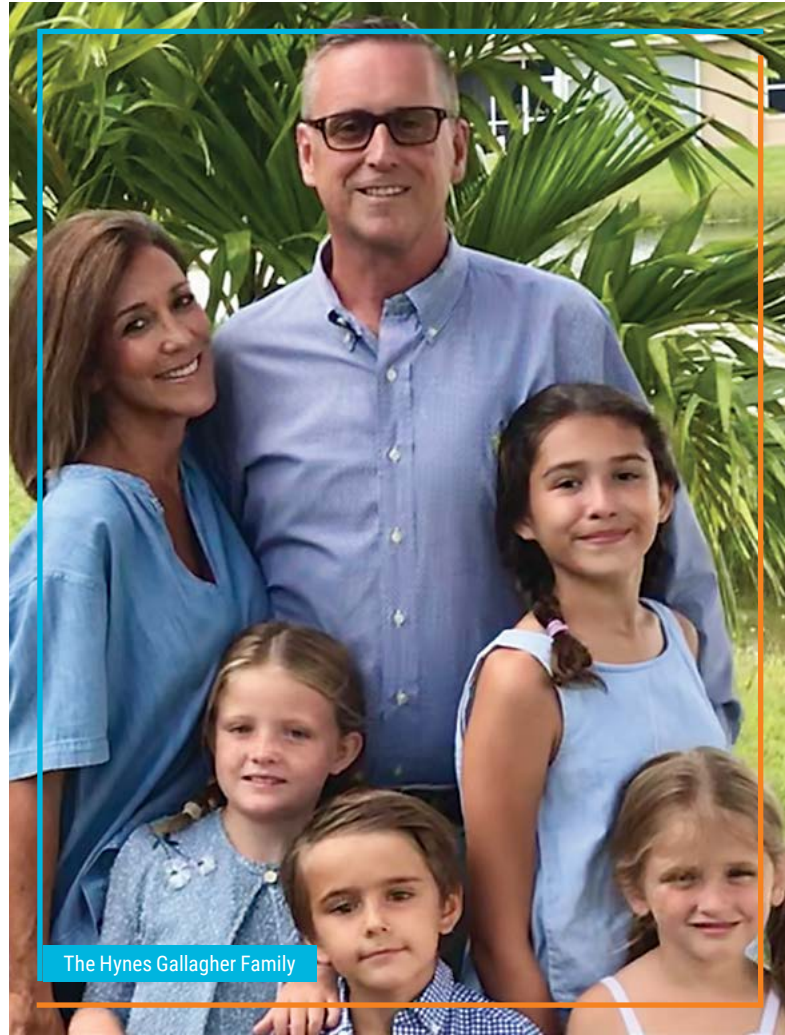
BY JENNIFER HYNES

Because my husband Kenny and I reconnected after dating in high school, there was no name more perfect for our daughter than Hope. Hope was diagnosed with tuberous sclerosis complex (TSC) when she was eleven years old—a day at the end of September we will never forget.

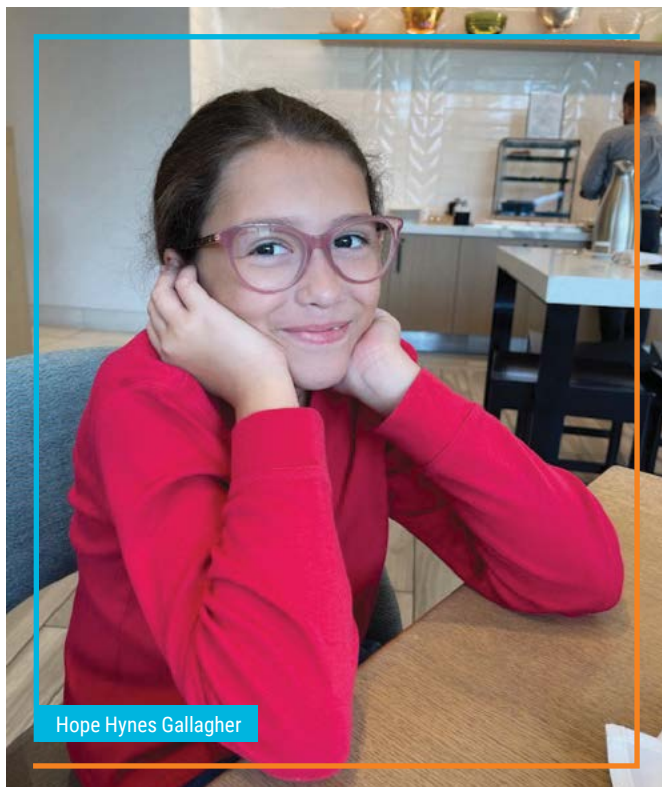
Hope had her first seizure at age six. Our child, who had always excelled at school, was struggling to keep up academically. She couldn't remember how to put on her shoes or that there were twelve months in a year. Despite a traumatic brain injury, her neurologist didn't believe the seizures and the traumatic brain injury were linked. Then, during a sleep study five years after her first seizure, Hope's neurologist saw something he thought needed a second opinion from a neuro geneticist.

When Hope was diagnosed with TSC, we were told not to Google it. There was also no plan of care—just the confirmation she has TSC. Of course, I immediately searched online for “tuberous sclerosis complex.” I wanted to know what we could do for Hope and what our lives were going to look like.

Thank goodness we found the TSC Alliance, because we wouldn't have known where to turn or what to do after her



The Hynes Gallagher Family



Hope Hynes Gallagher

diagnosis. We were paired with wonderful people who helped us figure out who to seek for care and support. We feel incredibly fortunate that a Google search led us to a group of people so fully committed to helping others like us.

Thanks to the TSC Alliance, our family connected with the wonderful TSC team at Cincinnati Children's Hospital. Dr. Darcy Krueger and the TSC team there help us to strive to stay on top of our daughter's healthcare needs.

Hope is now thirteen years old. Although she's now seizure-free, Hope continues to struggle academically, partly because of dyslexia and partly because of medical appointments and therapy sessions. We are homeschooling Hope to accommodate these challenges.

Our newest challenges are related to TSC-associated neuropsychiatric disorders (TAND). At the same time, we're trying to prepare for Hope's needs as she transitions into adulthood and what it will mean for her. These challenges include finding an advocate for her medical needs (such as organ checks), navigating Supplemental Security Income (SSI)/Disability, housing needs, etc.

It would be amazing if a cure could be found in Hope's lifetime. Our wish is for Hope to experience a long, healthy, happy life with a family of her own and to live independently. Hope is enrolled in three clinical studies, which makes her feel she is

actively engaged in helping to find a cure for TSC, and she also participates in the Biosample Repository.

As we reflect on our life as a couple and as a family, we realize the TSC Alliance helped us to understand Hope could benefit by seeing an occupational therapist, a physical therapist and a neuropsychologist. Before, we didn't know what steps to take in a plan of care for Hope.

There are some days we can almost put Hope's TSC out of our minds. On other days we are still coming to grips with

lifestyle changes and making tough choices. At times, a happy occasion can be tinged with a tiny bit of sadness or a bitter-sweet feeling.

We continue to be as involved as we can be with supporting the TSC Alliance as they seek a cure for Hope and other individuals with TSC who are also looking for answers and who may be more profoundly impacted. We hope sharing our story may move someone enough to contribute to the research the TSC Alliance is doing.

Government advocacy

House adopts bipartisan amendment increasing TSCRP to \$10 Million

On September 29, the U.S. House of Representatives approved its version of the fiscal year 2024 Defense Appropriations Act. During debate, the House approved by voice vote a bipartisan amendment offered by Representatives Jamie Raskin (D-MD) and Brian Fitzpatrick (R-PA) to increase funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense (DoD) from its current level of \$8 million to \$10 million.

This incredible accomplishment would not have been possible without the advocacy of the TSC community, dating back to our March on Capitol Hill and more recently emails and phone calls by dozens in our community asking their Representatives to support the amendment.

This action is not final, as the House bill must be conferenced with the Senate version of the Defense Appropriations Act, which may soon come to the Senate floor. The TSC Alliance will continue to work with our champions in the House and Senate to ensure that the full \$10 million appropriation for the TSCRP is included in the final version of the Defense Appropriations Act.

State advocacy efforts move forward

The TSC Alliance is also involved with advocating for TSC research

and care on the state level. Current initiatives are taking place in Alabama, Maryland and Missouri.

The Alabama State Legislature appropriated \$250,000 funding to support the University of Alabama at Birmingham (UAB) TSC Center of Excellence. Rep. Chris Pringle helped champion this state initiative. The UAB TSC Center of Excellence, located in Birmingham, was the first of its kind in the Southeast, serving patients with an established or suspected diagnosis of TSC. This funding will be targeted to support the TSC Clinic infrastructure and the UAB TSC research program. The UAB TSC Clinic is a TSC Alliance Center of Excellence and is co-directed by Martina Bebin, MD, MPA, and Bruce Korf, MD, PhD.

The Maryland state budget included continued appropriations of \$500,000 for the TSC Center of Excellence in 2023. Directed by Peter Crino, MD, PhD, Chair, Department of Neurology, University of Maryland School of Medicine, the TSC Center of Maryland integrates world-class clinical care with research, education, and outreach. This clinic provides clinical evaluation, care and treatment in collaboration with the Clinical Center for Adults with Neuro-Developmental Disabilities for adults with autism, intellectual disability and epilepsy. The TSC Center of Maryland also provides Maryland residents access to internationally recognized experts in adult TSC care.

The Missouri State Legislature appropriated \$500,000 in the state's 2023 budget for the TSC Centers of



Missouri. Directed by Michael Wong, MD, PhD, Professor of Neurology, Pediatrics, and Neurobiology, Washington University School of Medicine, this TSC Center of Excellence implements important new initiatives including expansion clinical care from childhood into adulthood, innovative clinical drug trials, and a laboratory drug screening program for TSC. The center is committed to a three-fold mission of basic science research, clinical patient research and care for TSC patients. In addition, this funding includes the TSC Clinic at Mercy Hospital in Kansas City, directed by Mohammed Ilyas, MD, to ensure access to TSC care throughout the state.

Save the date: 2024 March on Capitol Hill

The 2024 March on Capitol Hill to advocate for federal funding for the TSCRP will take place February 27-29, 2024, in Washington, DC. There are opportunities to participate either in person or virtually. Please contact Katie Smith, Director, Government & Global Affairs, at ksmith@tscalliance.org for additional information on how to participate.



TSC community needs and priorities shape new 2024-2028 Strategic Plan

Throughout 2023, the Strategic Planning Committee worked closely with TSC Alliance staff, Board of Directors and community members to update the organization’s next five-year strategic plan for 2024-2028. Committee members represented a diverse cross-section of the TSC community, as well as clinicians, researchers and advisors.

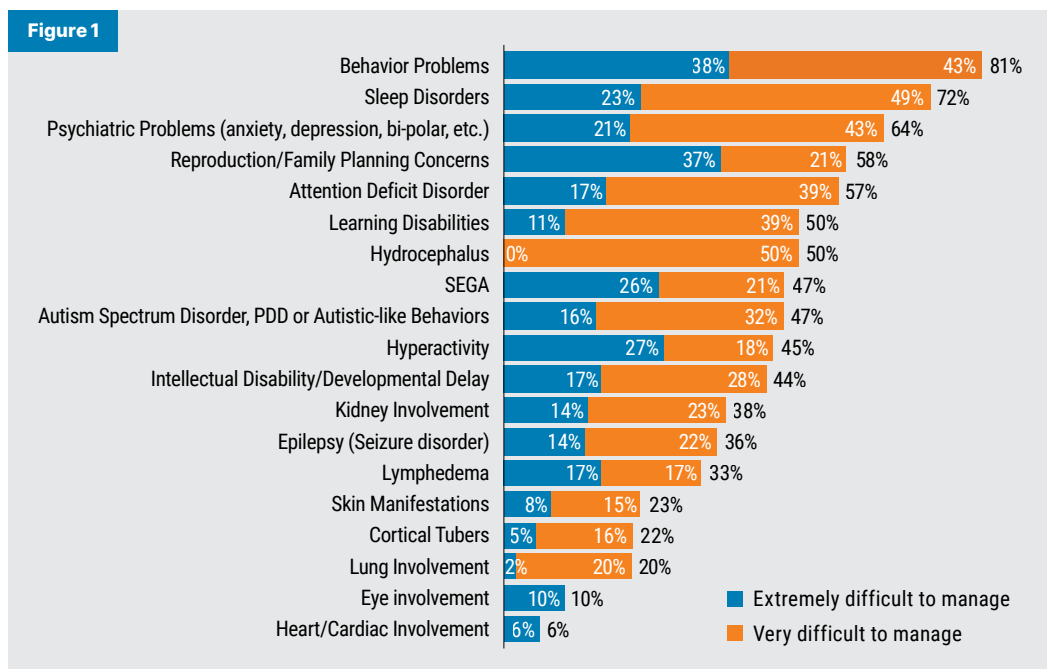
The foundation of the strategic plan rests on understanding the needs, challenges and priorities of the TSC community. To gain this understanding, the Strategic Planning Committee held a joint session at the March 2023 Board of Directors meeting in conjunction with the Volunteer Leadership Summit. The joint workshop focused on discussing the organization’s programs and priorities and gathering feedback from the board, staff team and community members in attendance to inform the strategic plan and prioritize programs and future areas of focus.

Additional input was solicited from the wider community via an online Constituent Survey which was launched in mid-January and closed in early April.

Beyond informing the 2024-2028 Strategic Plan and understanding the biggest areas of need within the community, the goals of the TSC Alliance’s 2023 Constituent Survey included measuring the organization’s performance in fulfilling its mission; evaluating various programs, resources and tools; and assessing how the organization performed in managing expectations during and after the pandemic.

The 2023 Constituent Survey was completed by just over 500 people aged 13 years or older, including individuals with TSC, parents or other primary caregivers, researchers and medical practitioners. The survey was modeled after previous iterations fielded in 2018 and 2010 to allow for the analysis of trends over time. However, for 2023, some sections were revised to better reflect the current state of the TSC community and organization, as well as to add in additional demographic questions on race, ethnicity and language to better understand the makeup of constituents establish a baseline for future benchmarking. **You can read full survey results on our website at tscalliance.org/2023surveyresults.**

Survey responses reflect the opinions and experiences of those who volunteered to complete the survey online. Figure 1 shows some highlights of what we heard.



The greatest challenges

When asked about the TSC-related medical issues that were hardest to manage, individuals with TSC and their caregivers were most likely to mention behavior problems, sleep disorders, psychiatric problems, reproductive and family planning concerns, attention deficit disorder and hyperactivity, intellectual and learning disabilities, developmental delays and autism spectrum disorder.

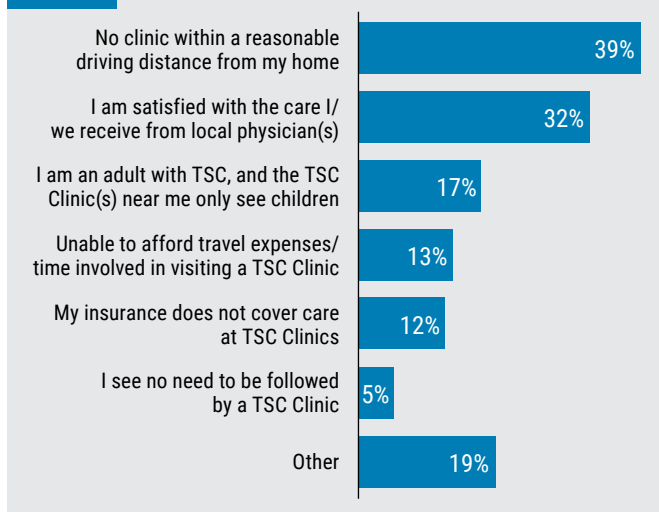
When asked about the TSC-related non-medical issues they'd experienced, the most common was educational issues (55%), followed by accessing social and recreational programs, accessing and navigating state waiver programs and finding respite services.

Getting health care for TSC

While 54% of caregivers and 38% of individuals with TSC are satisfied with the care they receive, only 20% of individuals and 35% of caregivers agreed with the statement that most health care providers are up to date in the latest treatments TSC for symptoms of TSC. More than a third (36%) of all individuals and caregivers find it difficult to find specialists familiar w/TSC within a convenient distance from their homes.

Just under two-thirds of survey respondents indicated they visit a TSC clinic. Of those who do NOT, 39% say it's because there's no clinic within driving distance of home (see Figure 2).

Figure 2

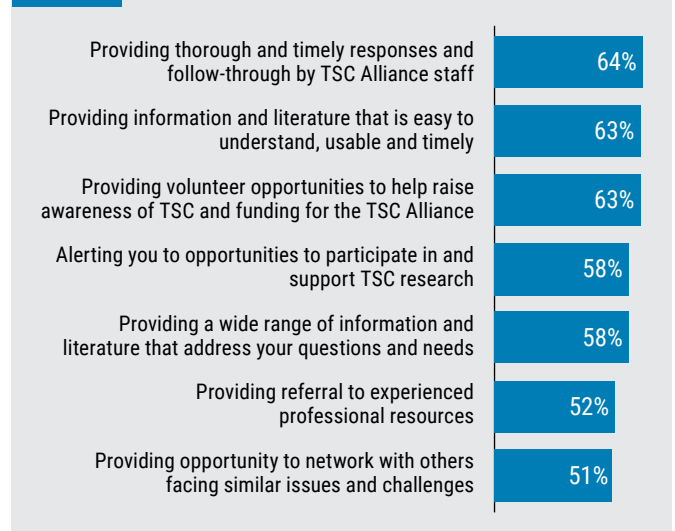


How well the TSC Alliance meets needs

Overall, 75% of respondents evaluated the TSC Alliance as excellent or very good in fulfilling its mission and 63% indicate they feel the organization has improved in that over the past five years.

The most highly rated TSC Alliance services were thorough and timely responses and follow-through by staff (64%); providing information and literature that's easy to understand, usable and timely (63%); and providing volunteer opportunities to help raise awareness of TSC and increase funding for the TSC Alliance (63%). Survey respondents indicated more room for improvement in providing referrals to experienced professional resources and providing opportunities to network with others facing similar issues and challenges (see Figure 3).

Figure 3



What the TSC Alliance should do next

Activities that respondents indicated were extremely or very important for the TSC Alliance to pursue included increasing funding for TSC clinical trials for drugs and/or medical treatments (70%); staying abreast of and advocate for legislative issues affecting individuals with TSC and their families (such as Medicare, Medicaid and medication access) (92%); and increasing funding of research relating to TSC-associated neuropsychiatric disorders (TAND) (62%).

The new strategic plan will be summarized in an "OGSM" document that describes the overall Objective of the TSC Alliance's work (the O in OGSM), its Goals (G), Strategies to achieve those goals (S) and Measures (M) to allow the Alliance to track performance on each goal. The new OGSM will be available on our website in January 2024.

Acknowledgements

- Strategic Planning Committee members:
 - Board Committee Members: Matt Bolger (Committee Chair), Lisa Carlton, Julian Gangolli, Dr. Tanjala Gipson, Jonathan Goldstein, Laura Marks, Sean Shillinger
 - Board Participants: Dr. Derek Bauer, Bill Joseph (Ex-Officio), Paul Waxlax
 - Non-Board Committee Members (Community Representatives): Rebecca Anhang Price, Meera Modi, Iris Mustich
 - Staff Representatives: Anne Wolfe (Staff Liaison), Dean Aguiar, Cynthia Arcuri, Jaye Isham, Shelly Meitzler, Ashley Pounders, Steve Roberds, Kari Rosbeck
- Special thanks to the team at Relevation Research for leading the analysis of the survey results and producing the final 2023 TSC Alliance Constituent; Avichal Jha for facilitating the writing and programming of the survey conducted by Intellisurvey; the Constituent Survey Task force who updated and reviewed the survey including Matt Bolger, Rebecca Anhang Price and Henry Shapiro; and the entire TSC Alliance staff for all their input throughout the strategic planning process.



Community Programs update

TSC Alliance introduces new Community Regions/ Collaborative Leadership Model

The TSC Alliance's Community Alliance volunteer model, which existed for more than two decades, included 36 volunteer branches spanning all 50 states. Community Alliance volunteers supported the needs of TSC families and individuals and provided the opportunity for in-person local support and connections, along with educational gatherings. Additionally, they organized fundraising events to advance research forward.

Because the TSC Alliance has experienced so much growth—both in terms of our organizational structure and grassroots community, it has become necessary to reimagine our volunteer program to enhance its effectiveness, so we are excited to introduce our new Collaborative Leadership Model and the transition from Community Alliances to Community

Figure 1. As we transition away from our former hierarchical volunteer structure, a circle offers a great metaphor for the Community Leadership Model since it embodies the concept of unity, cohesion and infinity.



Regions. The primary focus of these new initiatives is to incorporate a comprehensive program that better addresses gaps in resources, community support, medical access and

communication between and among the TSC Alliance and our thriving network of volunteer leaders.

The core of the new platform will consist of 15 Community Regions covering all 50 states. These regions were determined based on the availability of resources, support options and access to medical care. We will continue to evaluate and adjust the boundaries of each region while leveraging community input to address barriers to providing consistent levels of support and resources across regions.

Community Regions will be structured around our new Collaborative Leadership Model (see Figure 1), which focuses on the TSC community first and foremost by ensuring access to local resources, support services and medical care, while also empowering current and future volunteer leaders to take the TSC Alliance to the next level.

The Collaborative Leadership Model and Community Regions represent a new era and will support the TSC Alliance in our goal to ensure everyone with TSC has what they need to live their fullest lives. The new platform will help us create a collaborative and highly motivated volunteer network that is engaged to provide community support, offer resources and help raise operating funds that align with the mission of the TSC Alliance.

As we grow as an organization, Community Regions will become stronger and more knowledgeable about local support programs and services; Community Leads will represent a more inclusive and collaborative community; and the TSC Alliance and our volunteer leaders will strengthen the presence of the underrepresented populations across the country

Volunteer Leadership Summit provides volunteers with tools to succeed

Each year, the TSC Alliance hosts our advocates in Washington, DC, for our annual Volunteer Leadership Summit and the March on Capitol Hill. This year, the events were held February 28 to March 2 with more than 100 volunteer leaders from across the country participating. The Volunteer Leadership Summit included educational opportunities about the current state of TSC research; tools they can use to better support their communities; Building Toward Action: Tools for Equity, Inclusion and Belonging; major TSC Alliance initiatives; and how to effectively organize educational events, community gatherings and fundraisers while prioritizing caregiver mental health and wellbeing.

Attendees included Community Alliance leads, Adult Support Resource leads, Community and Support leads, Community Fundraising leads, Education Peer Mentors, Future Leaders, Clinic Ambassadors/Medical Access leads and Government Action leads.

Thank you to our generous sponsors for making this annual leadership training possible, including Presenting Sponsor Jazz Pharmaceuticals as well as Neurelis, Nobelpharma, UCB Inc., BridgeBio, Mallinckrodt, MassMutual SpecialCare and Marinus Pharmaceuticals.

2023 Regional TSC & LAM Conference Series was a huge success



Co-hosted by the TSC Alliance and The LAM Foundation, the 2023 TSC & LAM Conference Series consisted of four educational events held in Denver, CO; Birmingham, AL; Washington, DC; and Seattle, WA with 350-plus total attendees. Sessions included genetics and the future of gene therapy, TAND, LAM and LAM research, seizures types and treatments, kidney manifestations and treatments, skin manifestations of TSC, clinical trials, interventions and caregiver mental health and well-being.

Thank you to our generous supporters, including Presenting Sponsors Jazz Pharmaceuticals and Nobelpharma along with LivaNova, Neurelis, Ovid Therapeutics, UCB Inc., Upsher-Smith LLC, Longboard Pharmaceuticals, Mallinckrodt Pharmaceuticals, Marinus Pharmaceuticals, MassMutual SpecialCare, BridgeBio, Noema Pharma and TotalCare RX.

Regional TSC & LAM Conferences and Transition Workshops planned for 2024

The TSC Alliance and The LAM Foundation will co-host two Regional TSC & LAM Conferences in 2024. These one-day educational conferences will again include local leading researchers and clinicians who specialize in TSC and LAM. They will offer families and individuals up-to-date information and the most recent treatment choices for those living with TSC and adults with TSC/LAM. In addition, participants will be afforded networking opportunities to engage with other families and individuals residing in the area.

Two one-day Transition Workshops will feature local clinicians and consultants with expertise in the transition from pediatric to adult health care, as well as the transitions from postsecondary education, encompassing further education, employment, and independent living. These workshops will specifically focus on individuals with TSC. Sessions will provide families and individuals with recommendations and resources detailing how and when to begin preparing for the transition to adulthood. In addition, participants will be afforded networking opportunities to engage with other families and individuals residing in the area.

Look for more information on these conferences, including locations, in early January 2024.

TSC Alliance begins new focus on reproductive and perinatal health



The TSC Alliance Reproductive and Perinatal Health Taskforce was established after the 2022 World TSC Conference, where families, individuals with TSC and healthcare providers expressed significant concerns regarding the lack of consistency and evidence-based literature to proactively guide reproductive and perinatal health in TSC. Additionally, a lack of data exists surrounding safe surveillance and management of woman with TSC/LAM during pregnancy and postpartum.

The new taskforce will examine the persistent healthcare crisis concerning women's rights and seek to determine the ramifications of changes in healthcare, impacting women with TSC and other substantial manifestations that could have profound, life-altering consequences if neglected. To better grasp these outcomes, the taskforce established a goal of developing evidence-based guided discussions for all TSC/LAM women so that together, we can understand the risks and benefits associated with pregnancy so each woman can decide her own reproductive health options. We would like to extend our heartfelt gratitude to the Samuels Family Foundation and Dr. Joshua Samuels for their generous sponsorship of this project.

The project is led by Ashley Pounders MSN, FNP-C (TSC Alliance Director of Medical Affairs) along with core leads

including Lara Friel, MD, PhD (Maternal Fetal Medicine); Derek Bauer, MD (Adult Neurology/Epileptology); Lyndsay Harshman, MD (Pediatric Nephrology/Renal Transplant); Joel Moss, MD, PhD (Adult Pulmonology); Sarah Weatherspoon, MD (Pediatric Epileptology); Mustafa Sahin, MD, PhD (Pediatric Epileptology); Elizabeth Cassidy, MPH (TSC Alliance Research Project Manager); and Ayat Abi (TSC Alliance Scientific Project Coordinator). See additional taskforce members at the end of this article.

A workshop was held with the taskforce on September 7 at the TSC International Research Conference in Washington, DC. The first part of the workshop emphasized multi-organ considerations related to pregnancy, encompassing aspects such as neurological, renal and pulmonary considerations. Participants also addressed topics including imaging throughout pregnancy, pharmacological considerations and variables from the TSC Alliance Natural History Database. This discussion laid the foundation for the subsequent segment of the workshop, which focused on perinatal health surveillance and management strategies. While several considerations overlapped with the reproductive health segment, the perinatal health portion specifically delved into cardiac manifestations, fetal imaging, perinatal neurologic evaluation

“Our goal is to bridge healthcare disparities, uncover underlying causes of morbidity and mortality in relation to pregnancy in TSC and explore solutions to promote reproductive and perinatal health for those affected by TSC.”

and genetic considerations. The workshop outcomes will be further outlined in a comprehensive literature review publication in 2024.

Key priorities

Addressing diverse medical aspects in pregnancy calls for a comprehensive, multidisciplinary strategy. As many of these topics overlap, the taskforce managed to identify the following key priorities to better understand the risks associated with pregnancy for individuals with TSC/LAM.

Maternal/Fetal

- Maternal/fetal medicine involvement to better understand pregnancy related complications such as pre-eclampsia, intrauterine growth restriction, preterm labor, preterm premature rupture of membranes, fetal hydrops, abruption, miscarriage and fetal demise
- Screening and support for mental health care during and post pregnancy
- Value of pregnancy questionnaires on anxiety and depression
- In vitro fertilization safety and options

Neurological

- Medication metabolism, clearance, and teratogenicity of anti-seizure medications (ASMs) including mTOR inhibitors
- Active SEGA surveillance with safe pregnancy delivery interventions
- Impact of disrupted sleep during pregnancy and postpartum phases on seizures

Renal

- Pregnancy-associated risks on renal AML
- TSC 2 / PKD 1 gene deletion counseling
- Managing cystic kidney disease during pregnancy
- Effect of estrogen on AML size and growth
- Alterations needed for hypertension treatment due to the teratogenicity of medications such as ACE and ARB during pregnancy

Pulmonary

- mTOR management preconceptionally through postpartum stages
- LAM delivery readiness

- The impact of pregnancy on pulmonary function secondary to fetal growth
- Determination of safe pulmonary function tests prior to pregnancy and in early pregnancy
- Risk for spontaneous pneumothorax during pregnancy

Perinatal

- Genetic counseling, testing and in vitro fertilization
- Neonatal EEG timing
- Delivery and risk monitoring for higher level of care based off manifestations identified
- Fetal imaging across the trimesters
- Cardiac care targets mTOR inhibitor use in expectant mothers, focusing on dosage and dual monitoring
- Postnatal recommendations regarding EEG and brain imaging

Next steps

The TSC Alliance Reproductive and Perinatal Health Taskforce identified key priorities across diverse disease states and care. Our goal is to bridge healthcare disparities, uncover underlying causes of morbidity and mortality in relation to pregnancy in TSC and explore solutions to promote reproductive and perinatal health for those affected by TSC. Together, we will transition from retrospective studies to prospective, longitudinal research on the often-neglected manifestations in TSC/LAM. This is just the beginning, and we look ahead with determination and hope, eager to take the next steps on this vital journey.

Additional Reproductive and Perinatal Health Taskforce members

- Rebecca Beroukhim, MD
- Jamie Capal, MD
- Asim Choudhri, MD
- Danielle Clark, RD
- Jennifer Glass, MS, CGC
- Stephen Hammes, MD, PhD
- Elizabeth Henske, MD, PhD
- Lyndsay Hoy, MD
- Shafali Jeste, MD
- Rachana Krishna, MD
- Vera Krymskaya, PhD
- Iris Mustich, MPH
- Hope Northrup, MD
- Tessy Paul, MD
- Stephanie Randle, MD
- Kate Mowrey-Richardson, MS, CGC
- David Ritter, MD, PhD
- Joshua Samuels, MD, MPH
- Sue Sherman, MHA
- Wendy Vitek, MD
- Paula “Emma” Voinescu, MD, PhD
- Emily Walsh, MD

For more information

Please contact Ashley Pounders MSN, FNP-C, at apounders@tscalliance.org with any questions.

2023 International TSC Research Conference sets stage for the future of TSC scientific breakthroughs

The 2023 International TSC Research Conference: *Fueling the Future* was held at the Omni Shoreham Hotel in Washington, DC, from September 7-9, 2023. Hosted by the TSC Alliance, the conference welcomed 256 participants from 25 different countries. Importantly, 15% of attendees self-identified as members of groups historically underrepresented in biomedical research. Thirty oral presentations, 59 poster presentations and four breakout discussion groups promoted collaborative discussions between scientific researchers, health care professionals and members of the TSC community.

To conclude the event, a joint session was held with individuals and families attending the Regional TSC & LAM Conference to convey the importance of recent research discoveries and discuss the current gaps in knowledge. This session highlighted the crucial need for increased communication, care and collaboration between researchers, physicians, biotech and pharmaceutical professionals and individuals with TSC and their family members to fuel future scientific breakthroughs and continue to improve the quality of life for everyone impacted by TSC.



Conference Co-Chairs Dr. Rebecca Ihrie and Dr. Shafali Spurling Jeste

The keynote address was presented by Martina Bebin, MD, MPA, from the University of Alabama at Birmingham (UAB). Dr. Bebin currently serves as Co-Director of the UAB TSC Center of Excellence and has 20-plus years of experience studying clinical epilepsy and TSC. Her presentation recapped the outcomes and impact of the PREVeNT Trial, which you can read more about on page 22.

During the opening night dinner, Anna Jansen, MD, PhD, was presented with the Manuel R. Gomez Award in recognition of her extraordinary scientific and humanitarian efforts to find a cure for TSC while improving the lives of those affected. Her work has significantly impacted the field of TSC research and led to the first dedicated funding for a grant on TSC-associated neuropsychiatric disorders (TAND). Additionally, 18 early career researchers were recognized with the Vicky H. Whittemore Travel Award based on their outstanding abstract submissions. Importantly, 39% of these individuals were from groups historically underrepresented in biomedical research.



Gomez Award recipient Dr. Ana Jansen (center) with Dr. Petrus de Vries and Kari Luther Rosbeck

Vicky H. Whittemore Travel Award winners with Conference Co-Chairs Dr. Shafali Spurling Jeste (left) and Dr. Rebecca Ihrle (right)



Early Career Researcher Symposium

Prior to the start of the main researcher conference, an Early Career Researcher (ECR) Symposium was held September 7. This meeting served as a platform for early-stage career researchers, including graduate students, postdoctoral fellows and junior faculty, to network, present scientific findings and engage in career talks with established faculty and physicians. There were 60 attendees representing 30 institutions and 11 countries. ECR Co-Chairs Nicole McDonald, PhD, and Uchenna John Unachukwu, PhD, gave opening remarks, followed by two sessions of short talks.

The first session focused on understanding mechanisms underlying neuronal TSC and epilepsy, while the second session centered on better understanding how TSC affects organs other than the brain.

Following the short talks, a career-development panel took place featuring four distinct panelists: Dean J. Aguiar, PhD; Shafali Spurling Jeste, MD; Tracy King, MD, MPH; and Shui-Lin (Stan) Niu, PhD. This panel offered participants the opportunity to engage with early career researchers and discuss funding opportunities from the NIH and DOD as well as various career paths. These discussions emphasized the importance of young investigators to find great mentors who can guide them throughout their career paths.

Chemical and Cell Biology

Opening the main research conference, the first session of talks described the molecular pathways altered in TSC and how these pathways might be exploited for the generation of new therapies. These findings spanned a wide variety of topics—including the immune system, nutrient availability, RNA modifications and extracellular vesicles—and how changes in these pathways contribute to the development of TSC.

Biomarkers and Ethics in Early Intervention

The second plenary session discussed the use of biomarkers in the early detection of TSC and raised discussion on the ethics of early intervention. Topics also centered on early detection and intervention strategies for other neurodevelopmental disorders, including autism, and how these research findings translate to the TSC field.

TAND and Epilepsy Research

The third plenary session concentrated on TSC-associated neuropsychiatric disorders (TAND) and epilepsy research. This section of short talks described the outcomes of clinical trials as well as the development of future interdisciplinary projects to improve access to resources for individuals and family members impacted by TAND.

Organoids and Cell Development

The fourth session of plenary talks emphasized the importance of developing novel and more complex models to study TSC. Presenters described the development of novel 3D research models paired with innovative imaging techniques to better understand the complex cellular interactions in TSC.

Hot Topics Advancing TSC Research and Clinical Care

The final session of plenary talks discussed current hot topics in TSC research and clinical care. These topics include ongoing clinical trials, developing online research platforms, increasing diversity in clinical trials, and caring for adult TSC patients.

Breakout Working Groups

Transition from Pediatric to Adults: Hosted by Jamie Capal, MD, and Elizabeth Thiele, MD, PhD, this breakout group

discussed the challenging role of transitioning TSC patients from pediatric to adult care and what measures need to be implemented to aid this transition. Major challenges include the need to transition care for multiple specialists, gender differences and the reality that not every patient can be near a TSC center of excellence for care. Potential solutions included establishing care networks, promoting research initiatives in this area, collaborating with outside groups including family navigators/social workers and developing an educational program for individuals looking to know more about TSC.

Neurodevelopment and Early Intervention: Hosted by Shafali Spurling Jeste, MD, and Daniel Vogt, PhD, this breakout group focused on the need to better understand the underlying mechanisms driving neurodevelopment disorders. Discovering these mechanisms could lead to better biomarkers and treatment options for individuals with TSC. To address the source of wide variability in neurodevelopmental outcomes, discussions emphasized the need for a large-scale effort to better understand the nuances and differences in outcomes. One example given was the difference in developmental outcomes in twins with TSC. Additionally, discussions led to the suggestion of a large-scale study that would include medications coupled with behavioral intervention to better assess the right treatment for each individual child with TSC.

Cellular Energetics and Metabolism: Hosted by Oded Volovelsky, MD, PhD, and Gina Lee, PhD, discussions in this breakout group centered on exploiting metabolic changes within TSC to develop novel therapeutic treatments and improve disease management. There was a general consensus that there may be potential to use metabolic and nutritional supplementations to overcome certain limitations of existing treatments. One example is that researchers observe increased lysine breakdown in TSC cells. Treating metabolic differences could serve as a therapeutic approach in the future.

Big Data and Single Cell Approaches/Analysis: Hosted by Rebecca Ihrie, PhD, and Laura Farach, MD, this breakout group discussed the importance of big data in advancing TSC research, while also highlighting the key challenges. Suggestions to improve collaboration and progress in big data research included making a centralized TSC-focused directory where researchers can view different datasets previously generated and view contact information for principal investigators. Another suggestion was to host a working group to define common data terms and definitions to ensure data analysis is consistent across disciplines and research groups. There was also a desire to create online portals and assemble data repositories for data from TSC patients around the world. This would enable the generation of more robust research studies in the future. Lastly, the ability to offer consulting on study design prior to starting research studies was suggested to ensure data sets are generated in a meaningful and consistent way.

Poster Session

Friday night's Poster Session featured 59 posters presented by academic and industry researchers. Of those posters, 30 had at least one presenter who was a first-time attendee of our conference. The areas of study in these posters included—but were not limited to—research of lung, brain,



kidney and skin manifestations in TSC as well as TAND, TSC genetics and cell biology related to TSC.

TSCi Workshop

The 2023 TSC International Workshop took place September 6-7 with 40 participants representing 21 countries. The workshop included updates from each country representative, a panel discussion on international investigator-driven and industry clinical trials and how to work better together, and an update on the TANDem project.



Acknowledgements

We sincerely thank our conference sponsors who so generously helped support this conference. They include the Presenting Sponsors Nobelpharma and Marinus Pharmaceuticals; Featured Sponsor Jazz Pharmaceuticals; Advocate Sponsors Neurelis, UCB Inc. and Upsher-Smith Laboratories LLC; Early Career Research Symposium Sponsor Aevion Pharmaceuticals; Session Sponsors GeneDX, Grin Therapeutics, Longboard Pharmaceuticals, Noema Pharma, Ovid Therapeutics and Psychogenics; Bronze Sponsor Total CareRX; and General Sponsor Seizure Tracker. We would also like to highlight grant support provided by the National Institutes of Health, the National Institute of Neurological Disorders and Stroke, the National Center for Advancing Translational Sciences, the National Cancer Institute and the National Heart, Lung and Blood Institute.

New international consensus recommendations for the identification and treatment of TAND published

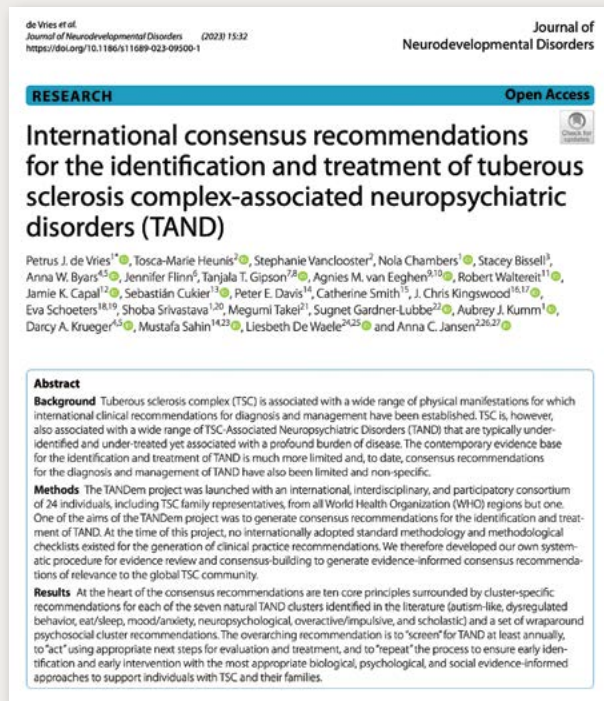
On September 14, 2023, the *Journal of Neurodevelopmental Disorders* published new international consensus recommendations to guide the identification and treatment of TSC-associated neuropsychiatric disorders (TAND). The article can be accessed free of charge at tsalliance.org/TANDarticle.

The publication was one of the outputs of the TANDem project – a 4-year collaborative and participatory research project led by Dr. Petrus de Vries (University of Cape Town) and Dr. Anna Jansen (Vrije University Brussels). The TAND consortium (tandconsortium.org) was created in 2019 after the TANDem project was funded through the Fund Dr. and Mrs. Charles Tournay-Dubuisson, curated by the King Baudouin Foundation (Belgium) and co-funded by the Tuberous Sclerosis Association (United Kingdom).

TANDem had three main aims: 1) to develop and validate a self-report, quantified TAND Checklist and to build it into a smartphone app; 2) to develop international consensus recommendations and a TAND toolkit of evidence-informed advice and information to families who live with TSC, also built into the smartphone app; and 3) to promote clinical knowledge and research on TAND by performing a range of networking and impact activities, establishing an international consortium of TAND researchers and supporting early career researchers.



The international consensus recommendations for TAND represent the most detailed advice on identification and treatment of TAND to date and were developed in a way that it should have relevance in all countries across the globe. “We realized two things very quickly—first, that the evidence-base within TSC was very limited and second, that health, social and educational systems around the world were very different,” said Dr. de Vries. We therefore developed the recommendations in a way that included evidence-informed advice also from outside



the TSC literature and presented recommendations as principles that can now be interpreted and implemented locally wherever people with TSC live.”

“We hope these recommendations can help tackle the treatment paralysis many families with TSC are confronted with. Healthcare professionals are often not familiar with TSC or TAND and feel unable to provide appropriated care,” added Dr. Jansen. “The recommendations consist of 10 core principles that are at the heart of TAND management, complemented by specific guidance for each TAND cluster such as, for example, the autism-like cluster, the dysregulated behavior cluster or the overactive/impulsive cluster. Tips and advice concerning self-care, impact on siblings and quality of life are listed under the wraparound psychosocial cluster. By reducing the complexity of TAND and of unique TAND profiles and providing advice at cluster level we hope to empower families as well as professionals to access and provide the most optimal and evidence-informed treatment and support for TAND.”

“Importantly, the development of these new TAND consensus guidelines was truly an international collaboration,” said Katie Smith, TSC Alliance Director of Government & Global Affairs. “This makes sense, because TAND is a global issue affecting people with TSC in all parts of the world. We certainly encourage everyone to share this article and the new guidelines with their health-care providers.”



Dr. Tena Rosser, Dr. Shafali Spurling Jeste and Dr. Vijay Vishanath

TSC Clinics “Up Close” TSC Clinic at Children’s Hospital, Los Angeles

The TSC Alliance has recognized the TSC Clinic at Children’s Hospital, Los Angeles (CHLA) since 2018. Headed by Co-Directors Shafali Spurling Jeste, MD; Vijay Vishwanath, MD; and Tena Rosser, MD, the TSC Clinic at CHLA is housed within the Pediatric Neurocutaneous Disorders Program. The multidisciplinary team spans many sub-specialties, including but certainly not limited to developmental neurology, nephrology, neurosurgery and dermatology. Dr. Jeste joined Drs. Vishwanath and Rosser in 2021. She is the Chief of Neurology and Co-Director of the Neurology Institute.

This article continues an interview series about the health-care teams around the world who provide excellent care to individuals and families with TSC.

What motivated you to choose this career path in TSC?

Dr. Shafali Spurling Jeste (SSJ): I was always interested in childhood development. In medical school I focused on

developmental disabilities and autism—there were so many interesting questions in the field at the time that had not a lot of answers—I wanted to learn about the brain and how it worked! TSC was my first point of entry into research, and my mentor at Harvard Medical School was studying at-risk infants whose siblings had autism. I had thought it would be neat to see if it was possible to identify predictors of autism in infants and have been working on and growing this research ever since.

Dr. Vijay Vishwanath (VV): Like Dr. Jeste, pediatric neurology caught my interest in medical school and during my first rotation in the clinic I knew there was no turning back. My mentor at NYU introduced me to TSC research.

Dr. Tena Rosser (TR): Like my colleagues, there is always a mentor who opens the door for you. The first time I came across TSC was when I saw an adolescent TSC patient in an inpatient psychiatry unit as a medical student. The patient had some seizures, and the care team needed help with

management. Dr. Greenwood, the attending child neurologist, took one look at the kid and knew immediately that he had TSC. After that experience, I religiously attended Dr. Bill McClintock's special TSC clinic on Saturdays during my child neurology fellowship training. The TSC field was so welcoming to me and nurtured my interests, and this is why I'm so passionate about carrying forward that tradition to young clinicians and researchers.

How does your clinic share responsibilities and communicate with each other?

VV: We operate as part of the Neurocutaneous Disorders Program, which is a family of clinics within the Division of Neurology at CHLA. All that to say, we have a wonderful group of cardiologists, dermatologists, nephrologists, psychiatrists—you name it—who are driven and have great passion for caring for kids with complex healthcare challenges. We try to get kids started as quickly as possible down the right track and tailor their care in a way that best supports them.

TR: Our wonderful designated TSC Nurse Coordinator, Katie Wanninger, helps keep us all on track. Without her, we wouldn't be such a well-oiled machine, delivering excellent care to patients and their families.

SSJ: What is special about CHLA is our incredible team who takes care of not just patients but their families as well. We get to know everyone, and the wonderful TSC community is such a rewarding part of all our jobs.

How do you raise awareness about TSC within your institution and community?

TR: We try to stay as visible as possible. Our colleagues across many disciplines know us as a troop of TSC clinicians and researchers. We have many inter-disciplinary talks at CHLA. Dr. Vishwanath and I were recently invited to present TSC lectures to other CHLA sub-specialists. Our TSC Clinic team also avidly participates in the annual Step Forward to Cure TSC walk!

What are the most challenging aspects of your clinical or research work? What are the most fulfilling?

VV: As clinicians operating in sometimes acute situations, one challenge we face is having to tell a family about a result they weren't necessarily expecting . . . when an inkling becomes true. It's our job to help create space for the family to acknowledge what is going on since these are big, impactful events and so often life can change on a dime. But on the flipside, what is fulfilling is doing everything we can to help. It is so rewarding to see kids make huge steps within just a handful of clinic visits.

SSJ: I wholeheartedly agree with Dr. Vishwanath. I'd like to add that CHLA is a safety net hospital. We take care of kids regardless of their ability to pay. Sixty percent of our

“What is special about CHLA is our incredible team who takes care of not just patients but their families as well. We get to know everyone, and the wonderful TSC community is such a rewarding part of all our jobs.”

patients are federally insured, and we serve a large population of non-English speaking families. These communities face immense challenges with resources and health literacy. This is what brought me to CHLA: to work with and serve this community day in and day out. It's helped me have a better understanding of what barriers exist to get patients involved in research; for example, it can be extremely hard to participate in a research study when there are other stressors facing a family. It's challenged me to make sure the programs I run are tenable and doable for them and to meet them where they are.

What is your clinic's approach to helping those affected by TSC-associated neuropsychiatric disorders (TAND)?

SSJ: We are expanding neurobehavioral expertise across the whole Division of Neurology. This means adding another full-time physician, Dr. Minnelly Liu, who is a full-time clinician.

VV: Dr. Jeste and the rest of us in Neurology have been building a robust service line as CHLA has made mental health care and behavioral health care a priority. We are building a huge group of clinicians in psychiatry/psychology, developmental behavior, etc. to create a TAND-based clinical program.

How do you balance your time between clinical/research practice and personal life? What do you enjoy doing outside of work?

TR: I try to stay as organized as possible because it is so hard to do everything, even though we all want to do so! Outside of work I try to spend as much time with my family and friends.

SSJ: Balance is always such a struggle, but when you're doing what you love, the sacrifices are worth it. Outside of work, I try to stay active, including running races and marathons. My sons are competitive tennis players, which also means I get to spend a lot of time sitting and stressing on tennis courts!

VV: I try my best to stay balanced just like my colleagues. For me, spending time with my kid who is in the Scouts of America is really reenergizing, and I always get to do something fun and active.



Top-line results from the PREVeNT Trial

BY STEVEN L. ROBERDS, PHD, CHIEF SCIENTIFIC OFFICER

Approximately 85% of individuals with tuberous sclerosis complex (TSC) experience epilepsy, which usually begins during infancy.

A baby's first seizures may be focal seizures, infantile spasms or a combination of both, and sometimes febrile seizures or status epilepticus may occur. (For an overview of seizure types, please visit tscalliance.org/seizures). Early-onset seizures left untreated are linked to a heightened risk of drug-resistant epilepsy, developmental delay and intellectual disability. Therefore, it is critical to treat seizures and get them under control as soon as possible.

An unanswered question has been whether in an infant born with TSC, it would be better to give a treatment that might *prevent* seizures because babies with TSC have such a high risk of developing seizures and drug-resistant epilepsy. However, not all babies with TSC develop epilepsy, so preventative

treatment of all babies with TSC would unnecessarily expose those infants who would not have developed epilepsy to a treatment, which might have its own side effects.

To identify which infants with TSC are at high risk of developing epilepsy, Dr. Martina Bebin led a study conducted at five centers to examine changes in EEG patterns over time. An EEG, or electroencephalogram, is a test measuring electrical activity in the brain. This study found changes on an EEG which can serve as a biomarker to predict well—although not perfectly—which babies are at risk of developing seizures. This enabled the PREVeNT Trial (PREventing Epilepsy using Vigabatrin in infants with TSC), the first multi-center double-blind placebo-controlled trial to evaluate preventative epi-

lepsy treatment in the United States. A double-blind placebo-controlled trial is a study in which neither the physician nor the



Dr. Martina Bebin

participant or their caregiver knows whether a participant is receiving the test therapy or a placebo. Vigabatrin, the current first-line therapy for treatment of infantile spasms in TSC, was used as the preventative therapy in the study, the results of which have been published (doi.org/10.1002/ana.26778).

Study design

The study group enrolled 84 infants between 2016 and 2020 at 13 TSC centers in the United States. Participants were monitored closely for the first signs of epilepsy. Participating infants received EEG screenings every six weeks in the first year of life, every three months during the second year and once at 36 months of age. Enrolled infants had not yet had any seizures. Infants who developed the EEG biomarker were placed randomly into one of two groups, either receiving preventative vigabatrin treatment or placebo. If seizures began in an infant in either group, the baby was started as soon as possible on vigabatrin, and other anti-seizure medications were added as medically appropriate.

Additionally, participants were assessed at 12, 24 and 36 months of age with standardized tests to evaluate their development in terms of cognition, communication, motor skills, social interactions, behavior, etc. With input from the U.S. Food and Drug Administration when designing the study, the primary outcome of interest was predetermined to be developmental measurements at 24 months of age. Additionally, the study also looked at many other outcomes, including occurrence of infantile spasms, focal seizures, and drug-resistant epilepsy.

What we learned

Preventative treatment with vigabatrin, when compared to preventive treatment with placebo, beginning when EEG biomarker changes were observed delayed the onset and lowered the overall occurrence of infantile spasms in infants with TSC.

However, there was no significant difference between the two groups in terms of drug-resistant epilepsy, focal seizures or cognitive and behavioral outcomes. While this was disappointing because the hope was that preventative vigabatrin treatment would be beneficial, much can be learned from the PREVeNT data.

In this trial, all participants were closely and frequently monitored, and parents and caregivers were counselled to watch for any signs of epilepsy in the infant. Therefore, when seizures began, treatment was started within a few days. The biggest predictor of poorer developmental outcomes was the age at which the EEG biomarker changes occurred: those infants whose EEG changes occurred prior to seven months of age had, on average, lower cognitive and behavioral scores than those whose EEG changes occurred later, regardless of whether they were in the preventative vigabatrin or placebo group.

What this means for the TSC Community

The PREVeNT results suggest that rapid diagnosis of TSC in infants, prior to having any seizure, followed by close monitoring and rapid initiation of treatment when seizures begin, is critical for ensuring the best outcomes possible. Treatment with vigabatrin remains the recommended first-line therapy for infantile spasms in TSC. PREVeNT researchers are also working to develop a consensus statement together with

researchers of the EPISTOP study, a European trial of similar, but not identical, design that also did not find significant cognitive and behavioral benefits with preventative vigabatrin. The EPISTOP trial did observe lower incidence of any type of seizure, infantile spasms, and drug-resistant epilepsy in the preventative vigabatrin-treated group. It is important for the global research and TSC community to work together to address remaining questions which are so important to those living with, and who have yet to be born with, TSC.

What comes next?

The PREVeNT trial generated a lot of additional data and resources which will be analyzed by researchers over the coming months and years, including MRI imaging, EEG and behavioral assessments, and blood samples.

“It is important for the global research and TSC community to work together to address remaining questions which are so important to those living with, and who have yet to be born with, TSC.”

Additionally, new clinical trials are ongoing in the United States and Europe. The U.S. study, TSC-STEPS (tscsteps.org), is evaluating the benefit of preventative sirolimus treatment compared to placebo. Sirolimus, also known as rapamycin, affects cells in the body differently than the way vigabatrin affects cells. Therefore, results of the TSC-STEPS trial could be different than the results of vigabatrin in the PREVeNT trial. The European study, ViRap, is also studying the effects of sirolimus and comparing it to effects of vigabatrin.

Acknowledgements

The biopharmaceutical company Lundbeck donated vigabatrin, brand name Sabril[®], for the trial. The TSC Alliance helped with recruitment by educating the TSC community about the trial and also provided supplementary funding for data analysis. The Bcureful Travel Fund and Pediatric Epilepsy Research Foundation provided supplementary funding to support travel of participants to clinical research sites. Research reported in this article was supported by the National Institute of Neurological Diseases and Stroke of the National Institutes of Health (NINDS) under the award number NCT028494571. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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You can honor a friend or family member for an important occasion with a gift to the TSC Alliance. It is a wonderful way to send a birthday or anniversary wish, or congratulations for retirement, a job well done, graduation etc. Please include the name and address of the individual being honored so that acknowledgement of your kind donation can be sent. TSC Alliance cards are also available if you would like to make a gift in honor of family, friends or colleagues. To receive tribute cards, contact Justin Martucci, Development Systems Manager, at (240) 638 4643 or jmartucci@tscalliance.org.

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Ms. Jennifer S. Segal-Geetter

Tribute(s) for Naomi Prosser
Carol Green

Tribute(s) for Julian Pultorak
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Tribute(s) for Elena R. Quintana
Mr. and Mrs. Christopher Quintana

Tribute(s) for Sarah Quintana
Ms. May Moore

Tribute(s) for Anthony Rasavage
Mr. and Ms. Mark Rasavage

Tribute(s) for Dominic Raya
Ms. Angeliqe Campos

Tribute(s) for John T. Richards
Ms. Karen M. Schuling

Tribute(s) for Christine Ritchie
Mr. Gary Caprio

Tribute(s) for Colleen Rivers
Mr. and Mrs. Charles Rivers

Tribute(s) for Asia Robertson
Mr. Karl I. Robertson

Tribute(s) for Emma Roche
Mr. Eugene Sweet

Tribute(s) for Kari L. Rosbeck
Mr. Henry P. Shapiro and Ms. Christy Hobart Shapiro

Tribute(s) for Deborah Rothweiler
Anonymous

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Tribute(s) for Grace Rubeck
Mr. and Mrs. Glenn Stevenson

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Ms. Rachel Murphy

Tribute(s) for Kayla Santico
Anonymous

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Ms. Jill Santos

Tribute(s) for PJ Scarr
Mrs. Christine Patchett
Ms. Kasey Walther

Tribute(s) for Eva (Maria) Schaedler Cadenas
Anonymous

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Mr. and Mrs. Joseph D. Garvey

Tribute(s) for Erin M. Schleich
The Thomas R. and Joyce M. Murphy Family Foundation

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Mr. Robert Davison

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Mr. and Mrs. Edward Sitar

Tribute(s) for Kaelie Schwab
Ms. Jill Trimmer

Tribute(s) for Dana Scroggins
Mr. and Mrs. Randy Wilson

Tribute(s) for Calin Scorby
Mrs. Carol L. Shonkwiler and Mr. George P. Johnson

Tribute(s) for Julie Scroggins
Mr. and Mrs. Tom Velasquez

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Mr. and Mrs. Bob Glick

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Mrs. Joan Williams

Tribute(s) for Brynleigh Shillinger
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Tribute(s) for Joshua B. Sims
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Tribute(s) for Stella Skillman
Anonymous

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Ms. Ellen Hoch
Ms. Heather Hopkins
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Mr. Michael Sheiowitz
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Anonymous

Tribute(s) for Rylee Skodras
Mrs. Paula Regan

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Ms. Denise C. Peterson

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Anonymous
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Ms. Kathleen A. Becker
Ms. Neerja Bhatia
Dr. Mina Ganapathy
Ms. Megan Kelperis
Ms. Alice Krogsaeter
Ms. Liz Leknickas
Mr. and Mrs. Tasvir Shah

Tribute(s) for Rallis Smith
Ms. Lytle Smith

Tribute(s) for Mia A. Spallone
Mrs. Tatiana Spallone

Tribute(s) for Nora Stempien
Mr. David Blake

Tribute(s) for Jason Stewart
Dr. Nancy Stark
Mr. and Mrs. Van Stewart

Tribute(s) for Adelyn Stubanas
Mr. and Mrs. James Heacock

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Mr. James Wilder and Ms. Margaret M. Curtin

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Mr. and Ms. Charles J. Marshall

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Mr. and Ms. Robert Moss

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Mr. and Mrs. James Markfort
Mr. Paul Thomas

Tribute(s) for Revi Thomas
Mr. Mark Craig
Mr. William G. Reinhardt

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Mrs. Tamara Tolley

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Mr. George Trundle

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Mr. and Mrs. Joseph F. Hovekamp
Mr. and Ms. Keith Turner

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Mr. Ricky Un

Tribute(s) for Rachel Underwood
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Mr. and Mrs. Richard L. Keister

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Ms. and Mr. Lisa Reyes

Tribute(s) for Lucas G. Vasquez
Ms. and Mr. Lisa Reyes

Tribute(s) for Riley Vogel
Mr. and Mrs. Robert F. Nolan Jr.
Ms. Jane Phillips

Tribute(s) for Dr. William Ward
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Mr. and Mrs. Richard D. Pace

Tribute(s) for Adrienne Wasserman
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Mr. John G. Waterbury

Tribute(s) for Clayton J. Wenderoth
Mr. David Browning
Ms. Elizabeth Flis
Ms. Rachael Todd
Ms. Eleanor Wenderoth

Tribute(s) for Addie Wenger
Ms. Lisa May

Tribute(s) for Cameron Wilson
Mr. and Mrs. Edward Cohen
Mr. Robert Cronin

Tribute(s) for Lindsey E. Wilson
Mr. and Mrs. Thomas Engle

Tribute(s) for Marko Wilson
Mrs. Christine Wilson

Tribute(s) for Mia Wojnilower
Ms. Brenda Schmand
Mr. Joel Wojnilower
Dr. Pamela Wojnilower
Mr. Samuel Wojnilower

Tribute(s) for Heather Wolfstone
Mr. and Mrs. Michael J. Wolfstone

Tribute(s) for Kelly Womack
Mrs. Karen S. Womack

Tribute(s) for Wayne Womack
Mrs. Karen S. Womack

Tribute(s) for Tyler Wooer
Mrs. Cathy Maassen
Mr. and Mrs. Jim Mitchell

Tribute(s) for Jamie Yates
Mr. and Mrs. Larry Berg

Tribute(s) for Judith Yates
Mr. and Mrs. Larry Berg

Tribute(s) for Ben Yeamans
Ms. Katelyn Yeamans

Tribute(s) for Alyssa Youmans
Mr. and Mrs. Tom Beyer

Tribute(s) for Tara N. Young
Ms. Joanne Young

Tribute(s) for Maria Zoumadakis
Mr. and Mrs. Lee J. Kapos
Mrs. and Mr. Mary Kapos

Tribute(s) for Blake Zuther
Ms. Ann Zuther

Memorials (December 1, 2022 – August 31, 2023)

Contributions are given to the TSC Alliance at the request of family members in memory of their loved ones. We extend our sympathies to the family and friends of those memorialized below. These generous contributions support the progress of our mission to find a cure for tuberous sclerosis complex.

Tribute(s) for Gary Anderson
Mr. and Mrs. Kevin Anderson

Tribute(s) for Katherine Ashley
Cherie Marshall

Tribute(s) for Jacob Barash
Mr. and Mrs. James R. Barash

Tribute(s) for Bill Barnes
Ms. Patricia Rambaud

Tribute(s) for Nancy J. Barnes
Mr. Elgin Dyer
Ms. Muriel Wright

Tribute(s) for Vincent Bassano
Mr. Joseph Bassano
Mr. Michael Bassano
Ms. Jessica Bush
Mr. Brett and Mrs. Stacey Dubin
Ms. Karen Johnson
Ms. Larissa Mason
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Mr. and Mrs. Jeffrey Beard
Mr. Harold M. Martin and Ms. Marie C. Block
Mr. and Mrs. Ronald McGuire
Mr. and Mrs. Ed Starr
Ms. Angela E. Wagner

Tribute(s) for Patricia Beatty
Mr. and Mrs. Phillip Beatty

Tribute(s) for Frank Beebe
Ms. Jan Abbott
Mr. and Mrs. Joseph C. Allione
Ms. Janet D. Beach
Mr. and Mrs. Charles L. Holliday

Tribute(s) for Jerome Bentfield
Anonymous
Mrs. Judy Bentfield
Mr. and Mrs. Richard C. Hulbert
Ms. Paula Ogrler
B. L. Radschlag
Mr. Chris Schoggen
Mr. and Mrs. Patrick J. Zurawski

Tribute(s) for Jerry Bentfield
Anonymous
Ms. Kristen Kennedy

Tribute(s) for Shorty Biedenbender
Mrs. Lori Biedenbender

Tribute(s) for Hailey Summer Bonk
Anonymous
Ms. Susie McCarty
Mr. and Mrs. Pablo Paul
Ms. Nancy Rheume
Ms. Wendy Van Slyke

Tribute(s) for Nathaniel Boyce
Dr. and Mrs. John R. Boyce

Tribute(s) for Kelly S. Bradley
Mr. and Mrs. Walter F. Bradley, Jr.

Tribute(s) for Allen Brown
Anonymous

Tribute(s) for Nathan Brown
Anonymous
Ms. and Mr. Kathy D. Gill

Tribute(s) for Debbie Bruce
Anonymous

Tribute(s) for Brielle Bulmer
Anonymous

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Mr. and Mrs. Richard A. Daniels

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Mr. and Mrs. Mike Cagle

Tribute(s) for Thelma Carter
Mr. Robert Gregg
Mr. William Stanton
Mr. John Taylor

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Mr. and Mrs. Jack Cenna
Coca Cola Foundation
Mr. and Mrs. Harvey Cohen
Ms. Christine Farman
Mr. and Mrs. Daniel J. Flavin

Mr. Stephen Perlman and Ms. Jo Anne Nakagawa
Dr. Paula Schauble
Mr. and Mrs. Jeff White

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Ms. Indira Challa

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Mr. and Mrs. Charles Rivers

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Ms. Diane W. Amdur
Anonymous
Mrs. Debby Teich
Ms., Patricia Torian
Dr. and Mrs. Stanley Worton

Tribute(s) for Jimmy Chrissy
Dr. William G. Ward and Dr. Corinne Ward

Tribute(s) for Susan Cimo
Ms. Kathleen L. Riley

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Ms. Kaitlin Colby

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Mr. Craig R. Bures
Ms. Julie Casertano
Mr. and Mrs. Brian McGuire
Ms. Eileen K. Moriarty
Mr. and Mrs. James Nicol

Mr. Robert Walsh

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Mr. and Mrs. Patrick J. Roche III

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Ms. Patti Pastori

Tribute(s) for Keiran Coyle
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Tribute(s) for Frank Criniti
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The Kuehn Family
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Mrs. Margaret Dolan

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Mr. and Mrs. Tikey Drossos

Tribute(s) for Sophia K. Drossos
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Mr. Jeffrey Emig
Ms. Terry Hammonds-Oswald
Mrs. Karen Kershaw
Mrs. Heather Kulaga
Ms. Joan Luthardt
Mrs. Shirley Wilkins

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Mrs. Marge Durschlag
Mrs. Sally Franklin
Ms. Linda Underwood
Mrs. Deborah Wilkins

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Mr. and Mrs. Fred Epplin

Tribute(s) for Ariella Felzenberg
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Ms. Jennifer O'Neill

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Mr. George Rapp

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Ms. Loretta and Mr. Curtis Kruse
Ms. Jeanine Lynch
Mr. and Mrs. Richard Ryan
Ms. Ellen Scherer
Ms. Marlene Sogan
Mr. Eduardo Vieira

Tribute(s) for Darren L. Flatin
Ms. Elaine Balken

Tribute(s) for Gary L. Flatin
Ms. Elaine Balken

Tribute(s) for Todd Flatin
Ms. Elaine Balken

Tribute(s) for Jim Frank
Ms. Valerie Logreira

Tribute(s) for Blake Givens
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Tribute(s) for John E. Green
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Tribute(s) for Gerald Greenbaum
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Mr. Russell Belin
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Mr. Ronald Schimel

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Ms. Susan Sideman

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Ms. Francis J. Monahan

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Tribute(s) for Gerald Horowitz
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Tribute(s) for Naomi Jackson Childers
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Tribute(s) for Naomi Jackson
Mr. and Mrs. Richard May

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Tribute(s) for Kenny Johnson
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Tribute(s) for Marilyn Johnson
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Tribute(s) for Glenice Karnes
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Tribute(s) for Patrick R. Kling
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Tribute(s) for Priscilla Korte
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Mrs. Audrey Malesky

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Mr. Frederic Marton and Mrs. Nina Zubkoff

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Tribute(s) for Emily McGaha
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Tribute(s) for Sean M. Miller
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Ms. Shanna Longa
Ms. Francine Machurick
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Ms. Kathleen Nelson
Mr. Richard Olympio
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Ms. Lisa Spadaro-Nau
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Mr. Keith Krueger

Tribute(s) for Brian Philo
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Tribute(s) for Eliana Pipek
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Mr. Greg Linsin and Ms. Julie A. Blum
Mr. and Mrs. John T. Richards Jr.
The Sperling Family Charitable Foundation
Ms. Lillian Trippett

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Mrs. Brenda Roelens

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Mr. Howard J. Schwartz

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First Presbyterian Church

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Mr. and Mrs. Christopher Rosbeck

Tribute(s) for Lewis Skrabanek
Anonymous

Tribute(s) for Michael Sorrells
Dr. and Mrs. Gary J. Sorrells

Tribute(s) for Susan K. Summers
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Pete Foster

Tribute(s) for Stephen Susag
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Tribute(s) for Donald L. Tash
Anonymous

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Lt. Col. Dick A. Trapp

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Mr. Parker Trewin

Tribute(s) for Dee R. Triemer
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Mr. and Mrs. James P. Tuite

Tribute(s) for Matthew Ulmen
Mr. and Mrs. Steven M. Ulmen

Tribute(s) for Calvin Vandeusen
Ms. Jill Thornton

Tribute(s) for Anthony Viola
Mrs. Christine Viola-Weiss

Tribute(s) for Fran F. Vogel
Mr. Arnold S. Vogel

Tribute(s) for Shu-Huei Wang
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Tribute(s) for Jeb Ward
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Mr. T. Bestor Ward
Dr. William G. Ward and Dr. Corinne Ward

Tribute(s) for Katherine Wegielewski
Ms. Della Kaplan
Ms. Susan Walsh

Tribute(s) for Clayton J. Wenderoth
Anonymous

Ms. Nancy Corbett
Mr. and Mrs. A. Gordon Davis
Ms. Andrea Fossa
Ms. Ellen Hutchins
Ms. Emily Kinsey
Ms. Rachael Todd

Tribute(s) for Jennifer Wiese
Mr. Mike Beile
Mr. and Ms. Ed Brooks
Mrs. Susan K. Cassler
Ms. Maria Fleming
Mr. and Mrs. David L. Kelly
Ms. Patsy Magnin
Ms. Patricia A. Parry
Mr. and Mrs. Stephen Patz
Ms. Jonni Pera
Ms. Eileen Piehl
Mr. and Mrs. Chris Quint
Mr. and Mrs. Roger L. Reitz
Mr. and Mrs. Joseph Sirokie
Ms. Barbara Spitzer

Tribute(s) for Aniyah Wilson
Ms. Tessalean Woods

Tribute(s) for Christopher T. Winkler
Mr. and Mrs. Walter Winkler

Tribute(s) for Ernie Winkler
Mr. and Mrs. Walter Winkler

Tribute(s) for Marlene Wolthuis
Mr. and Mrs. Charles T. Wolthuis

Tribute(s) for Nicolas Wolthuis
Mr. and Mrs. Thomas Hooker
Mr. and Mrs. Charles T. Wolthuis



Smart ways to give before 2023 ends

Would you like to finish this year with a gift to the TSC Alliance that maximizes your impact and reduces your taxes? Consider the four smart options below.

Make an immediate difference

When you support the TSC Alliance by simply writing a check, you make great things happen and may receive a federal income tax charitable deduction. If you itemize, you can write off the amount you're donating, resulting in lower taxable income. Unsure of whether your gift is tax-deductible? Contact your financial advisor or tax consultant.

Did you know? Your envelope must be postmarked on or before December 31 for your donation to qualify this year.

Use appreciated securities

By donating appreciated securities you have owned for longer than one year, you receive the same income tax savings as you would by making a gift of cash. You also eliminate any tax on the appreciation.

Did you know? If the securities are electronically transferred to TSC Alliance, the gift date is the day the securities enter our account – *not* the date you ask your broker to make the transfer.

Contribute to your donor advised fund (DAF)

Add funds to an existing DAF or open a new one for the TSC Alliance by a written agreement.

Did you know? You qualify for a tax deduction when you make a gift to a DAF, without immediately having to choose the organizations you want to support. If you are ready to start making an impact with your DAF, consider recommending a grant (or recurring grants) to support the TSC Alliance.

Make a gift from your IRA

If you are 70½ or older, you can give any amount up to \$100,000 from your IRA directly to the TSC Alliance. (Note: This amount will be higher in subsequent years to adjust for inflation.) You will not pay income taxes on the transfer. If you are required to take minimum distributions, you can use your gift to satisfy all or part of your obligation. Your IRA administrator must remove the funds from your account by December 31 for your donation to qualify this year.

Did you know? If you have check-writing features on your IRA, your check must clear your account by December 31 to count toward your required minimum distribution for the calendar year.

The countdown is on

As we approach the end of the year, we are happy to help ensure you realize the greatest benefit for your kindness. Please contact Lisa Moss, Vice President, Donor Relations, at (800) 225-6872 or lmoss@tsalliance.org for assistance.

Listen to our podcast series

TSC Now is the TSC Alliance's podcast series about tuberous sclerosis complex (TSC). Each episode, host Dan Klein, Director, Digital Platforms, interviews clinicians, researchers, TSC Alliance staff and community members about topics like breakthroughs in research, ongoing clinical trials, new resources and more. Below is a summary of episodes released in 2023.

Episode 42: Understanding seizure clusters

Dan interviews James Wheless, MD, Director of the Neuroscience Institute and Comprehensive Epilepsy Program and Co-Director of the TSC Center of Excellence at Le Bonheur Children's Hospital. Dr. Wheless describes what seizure clusters are, why they are a medical emergency and how new rescue medications can provide peace of mind to people who suffer from seizure clusters. This episode was sponsored by UCB, Inc.

Episode 43: The TSC-STEPS Trial

Dan interviews Darcy Krueger, MD, PhD, Director of the TSC Center of Excellence at Cincinnati Children's Hospital. Dr. Krueger provides an overview of the TSC-STEPS trial, the eligibility requirements, risks and benefits to participation, and what participation entails for families. He also discusses how the trial builds off findings of earlier intervention trials and may be part of a greater shift in the paradigm of care for those with TSC.

Episode 44: Rare conversations

Dan interviews Justine Ravindranath, Commercial Operations Manager at Nobelpharma America. Justine shares the findings of a panel discussion with young adults with TSC. He also talks to Iris Mustich, an adult with TSC and TSC Alliance volunteer who was awarded the Keith Hall Distinguished Leadership Award during the 2023 Volunteer Leadership Celebration. She shares her experience growing up with TSC, connecting with other adults during the pandemic and what ultimately inspired



her to volunteer. This episode was sponsored by Nobelpharma.

Episode 45: The 2023 International TSC Research Conference

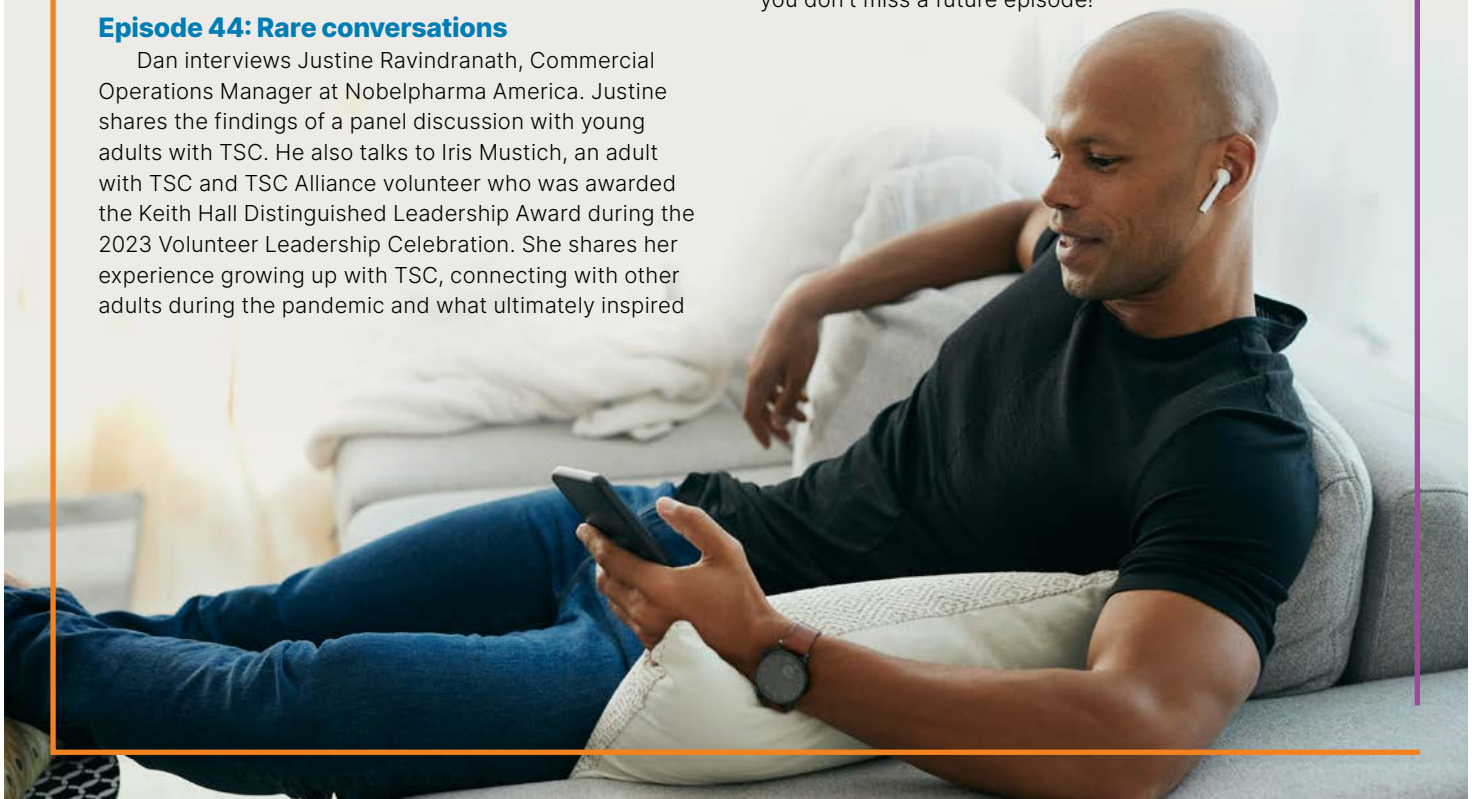
Dan interviews Shafali Jeste, MD, and Rebecca Ihrie, PhD, co-chairs of the 2023 International TSC Research Conference: *Fueling the Future* held in Washington, DC September 7-9, 2023. They discuss how the conference fosters collaboration between researchers, what presentations most excited them, and how researchers and the TSC Alliance can carry the momentum of the conference forward.

Episode 46: Understanding drug resistant-epilepsy and treatment options

Dan interviews Karen Keough, MD, a child neurologist at Child Neurology Consultants of Austin. She defines drug-resistant epilepsy (DRE), explains how lack of seizure control can impact someone's quality of life and shares some treatment options beyond medication, including surgery, dietary therapies and neuromodulation devices. This episode is sponsored by LivaNova.

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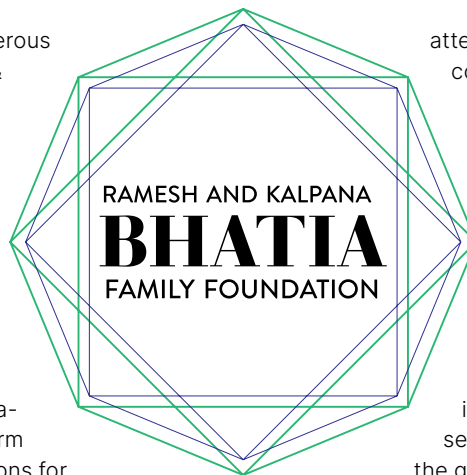


Anya's Accelerator advances TAND research

In 2022, the TSC Alliance received a generous \$2.5 million donation from The Ramesh & Kaplana Bhatia Family Foundation, which established Anya's Accelerator, a three-year project, to help address filling gaps in biomarkers for TSC-associated neuropsychiatric disorders (TAND). In the TSC Alliance's 2018 and 2023 constituent surveys, TAND was identified by the TSC community as posing as one of greatest challenges in terms of symptom management and coping.

The goal of Anya's Accelerator is to catalyze the development of biomarkers to inform clinical care and development of interventions for autism and other impactful aspects of TAND. Outcome research will be utilized to refine and develop patient-reported outcome (PRO) measures, investigate biomarkers using analytical methods and collaborative data analysis and develop preclinical TAND animal models to test candidate drugs in the later stages of the program. These projects will allow for the development of new TAND interventions and discoveries.

In April 2023, the TSC Alliance hosted an Innovation Workshop to focus on identifying biomarkers and predictors of TAND through collaborative discussion of existing blood-based biosamples and data generation through proteomic and genetic sequencing methods. Workshop



attendees included scientists, clinicians and community leaders in TAND blood-based biomarkers, data analysts and industry partners interested in supporting new TAND discoveries. The workshop led to a prioritization of protein and DNA sequencing of blood collected from participants in a clinical trial focused on understanding the natural history of TAND development.

The Anya's Accelerator program will begin proteomic analysis of samples in the final months of 2023 and genetic sequencing beginning early 2024. We hope the generation of data will allow for researchers to find correlations with specific TAND manifestations and severity to therefore focus future deeper research questions in TAND in relation to drug development, treatment and symptom management.

The 2023 TSC International Research Conference also included preliminary meetings surrounding the refinement of patient-reported outcomes (PROs) surrounding autism, anxiety and other TAND manifestation, and how they might be integrated into the TSC community.

The TSC Alliance is working toward creating a multi-national focus group of TAND experts, neuropsychologists, psychiatrists and TSC community members to measure what matters to individuals with TSC and TAND through PROs.



In collaboration with the TSC Alliance, Agnies Van Eeghen, MD, PhD, an intellectual disability specialist from Amsterdam University Medical Center and the TANDem Consortium, will lead efforts in PRO development for TAND. Dr. Van Eeghen's expertise in patient-reported outcome measures (PROMs) in genetic neurodevelopmental disorders will allow for a guided perspective in the



PRO work of the Anya's Accelerator TAND initiative.

The TSC Alliance continues to innovate and help facilitate discoveries with the potential to better the lives of those individuals and families living with TAND. We are optimistic that the collaboration between researchers, clinicians and the TSC community will bring together hope, in-hand with new understanding of TAND for a better future in TSC.

2023 Future Leaders make a difference

The Future Leader Class of 2023 is approaching its conclusion, and each made an impact by participating in the program. This year's graduating class is comprised of eight exceptional individuals: Rebecca Berger, Sara de Valle, Rebecca Fleming, Anna Galvin, Bao Heffron, Meghan Nazareno, Sydney Turner and Kylee Watts.

As part of the TSC Alliance's annual March on Capitol Hill, the 2023 Future Leaders actively participated in congressional appointment, which resulted in securing vital

Federal TSC research funding. In addition, they created a social media campaign to promote May as National TSC Awareness Month. As a final project, they intend to launch a podcast series for young adults/adults and siblings of TSC individuals. We have high hopes for their future endeavors, because it is evident they possess a strong desire to make a difference.

"As a leader in neurology for three decades, UCB is proud to support the Future Leaders who get involved with local Community Alliances to offer support while raising awareness of TSC. These Future Leaders provide much needed peer-to-peer support and build lifelong connections with others in the community. UCB congratulates the 2023 class of Future Leaders and is proud to support this important TSC Alliance program." – Brad Chapman, Head of U.S. Epilepsy & Rare Syndromes, UCB Inc.



2023 Future Leaders with Gail Saunders, Director of Community Programs (left) and Carly Kaye, Community Programs Manager (right)



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TSC Navigator is an easy-to-use online tool to help guide individuals and families through the complexities of TSC across the lifespan, proactively manage their care and live their fullest lives.

TSC Navigator is supported by Ovid Therapeutics and Marinus Pharmaceuticals.



Visit tscalliance.org/tscnavigator

