

PERSPECTIVE

A MAGAZINE FROM THE TSC ALLIANCE



Spring 2024 • VOLUME 156



50 Forward:
how past progress
fuels future
breakthroughs

COVER STORY | PAGE 8

**Learn how to participate in our
TSC/LAM research efforts**

PAGE 7

Reshaping the future of TSC

PAGE 16

**50th anniversary gala
scheduled for October 25**

PAGE 18

**Highlights from the 2024 TSC
Alliance Summit**

PAGE 20



Message from leadership

In 1974, four moms from Southern California – doing the best they could for their children – formed this organization and in doing so started a community. For the next 50 years the TSC Alliance and the TSC community have forever changed what we know about tuberous sclerosis complex (TSC) and what living with this disease looks like.

Today, we still work diligently to change the future for everyone affected by tuberous sclerosis complex (TSC) by focusing on ensuring access to lifelong care, furthering TSC research, implementing preventative clinical trials and expanding our efforts into new areas such as reproductive and perinatal health. This issue's cover story, starting on page 8, is not only a meaningful reflection on our past – it also sets the stage for the next 50 years.

Research has always been a crucial part of the TSC Alliance's mission. On page 13, you'll read about Drs. Bonnie and Jonathan Rothberg's almost three decades of steadfast support. The organization is eternally grateful for their commitment to moving research and community education forward.

Throughout 2024, we are celebrating 50 years of progress and promise by sharing historical facts, photos, accomplishments, public service announcements and much, much more. Be sure to follow @tscalliance on all social media platforms, where we also hope you'll share your favorite memories. You can also see the ad on the back page of

this issue to sign up for our mail list if you haven't done so. We are so proud to revere and celebrate the legacy set by our founders, the dedication of each generation of our community and leadership since, and with a firm focus on a future where everyone with TSC has what they need to live their fullest life.

The TSC Summit in Washington, DC, just wrapped up in February. It included our annual March on Capitol Hill, which featured a Congressional Briefing emceed by our long-time friend, actor Jim O'Heir, hosted by U.S. Senator Eric Schmitt and with presentations by the head of the Congressionally Directed Medical Research Program and the National Institutes of Neurological Disorders and Stroke; two days of Volunteer Leadership Training; Board of Directors meetings; and finally, our beloved Volunteer Appreciation Dinner. You will find more information about all of these in the following pages.

The TSC Alliance would like to salute and thank the following board members who finished their terms last year: Dr. Peter Crino, David Coit, Rob Grandia, Dana Holinka, Diane McSwain, Tara Zimmerman and Endowment Fund board members Mike Augustine and Hal Tearse. We'd also like to welcome incoming board members Frances Briones, Andrew Sperling and Mark Spotts and Endowment Fund Board members David Johnston, Megan Self and Mark Schaengold.

Our Step Forward to Cure TSC® walk series is in full swing, and we will

offer two Regional TSC Conferences and two Transition Workshops this year. We encourage you to participate in the walks and the conferences or workshops as they offer great opportunities to connect with others in the TSC community. On page 18, you'll find information about our 50th Anniversary Gala, set for October 25 in New York City, which offers another opportunity to join us in our golden anniversary celebration.

From the very beginning, the TSC community has always – always – been the heartbeat and lifeblood of the TSC Alliance. Every accomplishment, every advance, every victory is due to your ongoing and unwavering compassion and commitment to the organization and to each other. We have much to celebrate together this year: hope no matter how complex.



Kari Luther Rosbeck
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PERSPECTIVE

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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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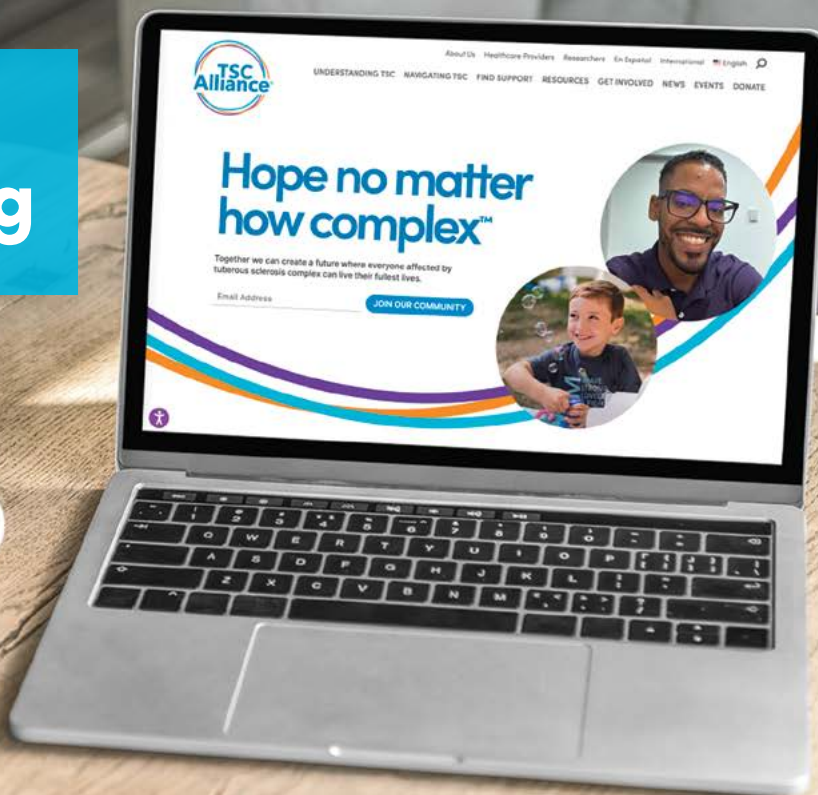
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Meet the new tscalliance.org



In partnership with our site designer Teramark, the TSC Alliance spent much of the last two years redesigning the organization's website at tscalliance.org, with the new site launching on Friday, January 26, 2024. Senior Director, Communications Dan Klein led the project.

On average, the website gets 20,000 monthly users. "Our website is the most important asset the TSC Alliance has in terms of generating awareness of TSC and educating and providing resources to those affected," Dan says. "So we really wanted to start from the ground up and make sure the new site incorporates best current web design practices, is accessible and most importantly meets the needs of those we serve." The last time the organization redesigned the website was in 2016.

The project kicked off on October 13, 2022, when the TSC Alliance and Teramark facilitated a focus group of 13 people from the TSC community. The group included parents of younger children with TSC, parents of dependent adolescents/adults and adults with TSC. The goal of the focus group was to learn about what people liked about our old site and what they found challenging. Feedback from participants drove decision-making about navigation, design and content for the new site. "We gained so many insights by just stepping back and listening to what the community had to say about what was working and not working on the old site," reflects Dan. "They were such crucial partners throughout this project."

The new site features a shift to a simpler navigation organized around call to actions rather than audiences. Content has been streamlined and optimized for viewing across devices. The design also reflects lessons learned from the development of TSC Navigator in 2021, and this easy-to-use tool has been expanded on the new site to better support individuals with TSC and their families throughout their lives. Digital resources – including our podcast series, publications and videos – now reside in a comprehensive resource library but also appear as related content on pages throughout the site. This allows visitors to take a deeper dive on topics relevant to them.

Another feature of the new site is the Stories of Hope page, which features diverse user-submitted stories about living with TSC and what gives them hope. "It was important to center the TSC community on the website, so when people come, they see their lived experience reflected there," Dan explains. Visitors can sort the stories by life stage to find perspectives that resonate with where they are in their journey.

The redesign process also allowed the organization to fully integrate the TSC Alliance brand as well as the new mission and vision statements approved in 2023.

The website redesign was made possible through sponsorships from Jazz Pharmaceuticals; Nobelpharma America, LLC; Livanova; Mallickrodt Pharmaceuticals; Marinus Pharmaceuticals; Upsher-Smith Laboratories, LLC; and MassMutual SpecialCare.

Special events



The TSC Alliance is proud to announce Nobelpharma America as the 2024 National Title Sponsor of the Step Forward to Cure TSC® walk series. Step Forward to Cure TSC is the TSC Alliance's largest annual fundraiser and awareness event.

Plan now to join us as we Step Forward to Cure TSC with a month-long series of in-person and virtual walks, runs and rides starting April 13 and concluding the weekend of May 18-19. Registration is free, with fantastic prizes and contests. Find out more today at stepforwardtocuretscc.org.

2024 event schedule

All dates are subject to change. Please check stepforwardtocuretscc.org for the latest details.

April 13	Fishers, IN
April 27	Nashville, TN Salt Lake City, UT
April 28	Renton, WA
May 4	Rock Hill, SC
May 11	Shepherdstown, WV Northglenn, CO
May 18	Irwindale, CA Chicago, IL Tulsa, OK West Chester, PA
May 19	Rockville, MD Carrollton, TX

The Step Forward to Cure TSC walks play a crucial role in raising funds for research, advocacy, community support services and educational programs for individuals and families impacted by TSC. By participating, fundraising, and spreading awareness, you become a vital part of the movement to create a future where everyone affected by tuberous sclerosis complex can live their fullest lives.

National sponsors





NYCRR Half Marathon/TeamTSC results

On March 17, 2024, five determined runners – **Ashleigh Dawertiz, Margaret Gabriel, Kristi Lengyel, Kimberly Moran Puerta** and **Taylor Ryan** – proudly represented the TSC Alliance as they took on the United

Airlines NYC Half Marathon. Their journey was not just about completing a challenging race but also about making a difference for those affected by TSC. Through their collective efforts, they raised an incredible \$20,742 to help advance the mission of the TSC Alliance.

If you are interested in joining Team TSC, please visit [tscalliance.org/TeamTSC](https://tscalliance.org/) to submit an interest form.



Team TSC (l-r): Ashleigh Dawertiz, Kristi Lengyel, Margaret Gabriel, Taylor Ryan and Kimberly Moran Puerta.

Luminate the Night

Congratulations to the TSC Alliance: Carolinas Community Region on hosting its fourth annual community fundraiser, Luminate the Night.

This year, the event raised more than \$13,000 to benefit the TSC Alliance. The participating families line their streets, driveways, and walkways with luminaries, which consist of a battery-operated tea light candle placed in 2-3 inches of sand inside a white paper bag.

A special thanks to organizers David and Karen Johnston, Heather Harden, and a host of volunteers.



Special events (continued)

Community fundraiser opportunities

Are you passionate about making a positive impact in your TSC community? Do you have creative ideas for hosting a fundraiser? We invite you to collaborate with us and host a community fundraiser to support a meaningful cause! Whether it's a charity auction, a fun run, a bake sale or any other creative event, your efforts can make a real difference.



Contact us today to discuss how you can get involved and organize a successful fundraiser that brings your community together for a great cause!

For more information, please contact Gail Saunders, Director, Community Programs, at gsaunders@tscalliance.org.

2024 Regional Conferences/Transition Workshops

The TSC Alliance will host two Regional TSC Conferences and two Transition Workshops in 2024 aimed at individuals with TSC and their caregivers. Attendees will also have networking opportunities to meet other families and individuals from the area. A \$10 registration fee per registration includes 2 breaks and a boxed lunch. Please note: Childcare will not be available at these events.



One-day Regional TSC Conferences will feature leading local researchers and clinicians specializing in TSC. Sites include:

- Chapel Hill, NC: Saturday, June 1
- San Francisco Bay Area, CA: Saturday, November 16

Workshops will feature sessions across the lifespan of TSC, including:

- Research updates, including upcoming clinical studies and trials for TSC
- Behavior and mental health
- Genetics and gene therapy
- Women's health issues
- Seizure types and treatments
- Kidney involvement and treatment options
- Skin manifestations and treatments



Presented by Jazz Pharmaceuticals Nobelpharma


One-day Transition Workshops will feature local clinicians specializing in the transition from pediatric to adult health care and transitions from postsecondary education that include further education, employment and independent living in individuals with TSC. Sites include:

- Memphis, TN: Saturday, August 3
- Salt Lake City, UT: Saturday, September 21

The sessions will provide families and individuals with recommendations and resources that provide timelines, resources, and supports available on how and when to start preparing for the transition to adulthood for those living with TSC.

Thanks to our Presenting Sponsors Jazz Pharmaceuticals and Nobelpharma America, LLC; Series Sponsors LivaNova, UCB and Upsher-Smith Laboratories, LLC; Supporting Sponsors Longboard Pharmaceuticals and MassMutual SpecialCare; Two Conference Sponsor BridgeBio; and One Conference Sponsor Insitro.

Please visit tscalliance.org/2024conferences for more information and to register. Sites and dates subject to change.



Learn how to participate in our TSC/LAM research efforts

Donate blood samples and provide behavioral testing results

The TSC Alliance's Anya's Accelerator program was established in Fall 2022 following an extraordinary donation of \$2.5 million from The Ramesh & Kalpana Bhatia Family Foundation. Anya's Accelerator seeks to develop quantifiable measures of TSC-associated neuropsychiatric disorders (TAND) to improve clinical care and research.

Anya's Accelerator is embarking on a transformational effort to identify blood-based markers that will help predict risk of TAND, progression, and response to treatment for TAND such as anxiety and autism. To achieve this, we need increased participation from the community that captures the diversity and severity of TAND symptoms to donate blood through the TSC Biosample Repository and to provide access to neuropsychiatric behavioral testing (e.g., ADOS, Vineland Adaptive Behavior Scales, etc.) for deposit in the Natural History Database. *All personal information and data are anonymized and cannot be used to identify you or your loved one.* Blood can be coordinated to be collected in your own home via mobile phlebotomy or through any Quest Diagnostics location.

TSC research is driven through our community, and we can't do it without you! We appreciate your support for TSC research. Please reach out with questions or your willingness to participate to Dean Aguiar, PhD, Vice President, Translational Research, and Elizabeth Cassidy, MPH, Research Project Manager, at biosample@tscalliance.org.

Coming soon: Self-Reported TSC/LAM Pregnancy Experience Survey

Women with TSC who develop renal AML and/or LAM face significant risks, especially during their childbearing years and pregnancy due to hormonal fluctuations. These risks are

compounded by a lack of comprehensive information, support and inconsistencies in surveillance and management within the TSC/LAM patient community regarding pregnancy and fertility. It's crucial to investigate key factors such as medication interactions, in vitro fertilization (IVF), complications during pregnancy and postnatal, fetal outcomes, personal experience and other relevant aspects to address these gaps in care and support for women with TSC/LAM facing these complex health challenges. Through a survey, we aim to gather data on the current sentiments, needs and concerns of women regarding pregnancy. This data will help us develop resources and research focused specifically on pregnancies in women affected by TSC/LAM.

The survey is specifically designed for women and/or their male partners diagnosed with TSC who are either currently pregnant, had a previous pregnancy experience and those of childbearing age (post menarche) who have future plans for pregnancy. Survey questions will include demographic data, experiences with pregnancy and/or infertility, perceived anxiety and worry surrounding getting pregnant, past or current discussions with providers surrounding getting pregnant while on certain medications, experience with pre-conceptive/prenatal counseling, and mental health during pregnancy. *Respondents will not be required to disclose any personal identifying information.*

The online survey will be released soon so be sure to watch your email and @tscalliance on our social media platforms, such as Facebook and Instagram.

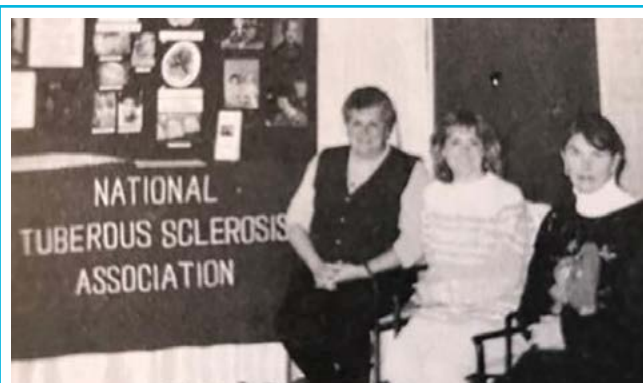
If you have any questions please reach out to Ashley Pounders, MSN, FNP-C, Director of Medical Affairs, at apounders@tscalliance.org for further information. Thanks to the Samuels Family Foundation and Joshua and Cheryl Samuels for their support of the Reproductive and Perinatal Health Initiative.

50 Forward: how past progress fuels future breakthroughs



The journey of the TSC Alliance began five decades ago when four moms were inspired to form an organization to challenge the status quo of tuberous sclerosis complex. Since then, we have been steadfastly committed to our mission of improving quality of life for everyone affected by TSC by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support.

Today, we are on the cusp of breakthroughs that will again shift the paradigm of this disease and redefine what life with TSC looks like. As you'll read in the following pages, the origins of these next breakthroughs can be traced along the stepping stones of progress throughout our history. Of course, all the advances we have seen start at the very beginning of our story.



NTSA 1974.

Today, we are on the cusp of breakthroughs that will again shift the paradigm of this disease and redefine what life with TSC looks like.

- **1974:** The first meeting of National Tuberous Sclerosis Association's (NTSA's) founders — Debbie Castruita, Adrienne Cohen, Susan (Diaz) McBrine and Verna Morris — is held in Southern California. Susan had previously sent a letter to *Exceptional Parent* magazine seeking other parents of children with TSC. From that initial meeting a community took hold and a movement committed to providing fellowship, generating awareness, pursuing knowledge and offering hope to all affected by TSC was underway.

“Getting those letters made me realize if we united, we weren’t ever going to be alone. So Adrienne, Verna, Debbie and I got together and started the movement.” —Susan McBrine



appropriated \$121 million to fund high-risk, high-reward research in TSC.

- **2002:** The TS Alliance, National Institute of Neurological Disorders and Stroke and the NIH Office of Rare Diseases Research convenes an international symposium in Chantilly, Virginia. At this meeting, researchers discussed the link between TSC and the mammalian target of rapamycin (mTOR) pathway, opening the door to mTOR inhibitors as a potential treatment. The following year, the TS Alliance and The LAM Foundation sponsored a clinical trial on treatment of kidney and lung manifestations using rapamycin. This was the first of 10 clinical trials in the years that followed testing the efficacy of mTOR inhibitors to treat SEGAs, angiomyolipomas, facial angiofibromas, LAM and epilepsy associated with TSC.
- **2010:** After seven years of clinical trials, the FDA approves the first drug (called everolimus) designated to specifically treat SEGAs associated with TSC. This was the first of three FDA-approved drugs specifically for TSC. These trials would not have been successful without courageous participation by those affected and the TS Alliance's

From genes to gene therapy: the power of investing in research

Funding research to develop new treatments for TSC has always been a priority for this organization. As our investments grew over the years and as we partnered with others to move research forward, progress became more tangible.

- **1984:** Ten years after the formation of NTSA, it funds its first ever research grant. Early investments paved the way for the cloning of the TSC2 gene in 1993 and the TSC1 gene in 1997. Now researchers had a starting point to understand the root cause of the disease and it was time to get others involved.
- **2000:** NTSA adopts a new logo and begins doing business as the Tuberous Sclerosis Alliance (TS Alliance).
- **2001:** After a decade of continued advocacy by the TSC community on the importance of federally funded TSC research, the organization obtains support from Congress to start the TSC Research Program (TSCR) at the Department of Defense Congressionally Directed Medical Research Program. To date, this program has

“In the next five to ten years we really do have to embrace some of the amazing advances happening in molecular and cellular biology. I think the concept of gene therapy in TSC five years ago was science fiction, but it’s actually on the table now, which I think is remarkable.”

—Peter Crino, MD, PhD, Professor and Chair, Department of Neurology, University of Maryland School of Medicine



commitment to educating the community about their role in research over the years. That same year the TS Alliance establishes the TSC Drug Screening program, an early precursor to another important platform.

To unravel the complex mysteries of TSC, including the variability person-to-person and the progression of the disease throughout a lifespan, the TSC Alliance invested in building tools to empower researchers with the data and samples they needed to test new treatments.

- **2016:** The TS Alliance introduces the TSC Preclinical Consortium with members from industry and academia to test the efficacy of candidate therapeutic drugs and advance the best to the clinical stage. The consortium developed five mouse models for both tumor growth and epilepsy/behavior in TSC and have tested 82 candidate drugs.
- **2021:** Following two years of planning, the TS Alliance formally rebrands to become the TSC Alliance.
- **2024:** Today the Preclinical Consortium is adding new mouse models around other manifestations of TSC, including autism, and seeking partnerships to test therapies beyond mTOR inhibitors, including gene therapy. Simultaneously, the TSCRIP is prioritizing research to develop, assess, and test emerging technologies including imaging and molecular therapeutic strategies, such as

gene therapy, to improve outcomes of TSC and has funded two studies looking at gene therapy in TSC.

Meeting the evolving needs of a growing community

From that initial meeting in 1974, volunteers at the National Tuberosclerosis Association spent hours taking phone calls and connecting with other families because they understood that they would have power in numbers. And over time, the organization grew.

- **1999:** Having connected with families across the country, NNTSA holds its first National Family Conference in Washington, DC. This conference provided a blueprint for community involvement and helped define priorities for the organization moving forward. That same year, the organization supported 20,000 people, including 11,000 family members and adults personally impacted by TSC.
- **2001:** TS Alliance launches volunteer outreach program, including formalizing volunteer branches called Community Alliances.
- **2005:** Recognizing the changing needs of people with TSC as they get older, the TS Alliance amends its Articles of Incorporation to be inclusive of people with TSC across their lifespan and continues to expand services for adults with TSC, including by hosting an Adult Summit and town halls, developing adult tracks at future Regional and World TSC Conferences, drafting adult journals and recruiting adults to serve in volunteer roles across the country.
- **2011:** The organization's commitment to supporting adults is formalized with the launch of an adult initiative. The goals of the initiative were to improve the quality of life for adults with TSC, advance our knowledge of TSC as it affects adults with the disease and include adults in helping to search for ways to improve treatments and change the course of the disease. The following year for the first time, adults with TSC participated as members of the organization's Grants Review Committee, giving them a seat at the table to help shape the direction of research.



Participants at the 2017 Externally Led Patient-Focused Drug Development meeting.

- **2017:** To highlight the unmet needs of those living with TSC & LAM, the TS Alliance sponsors an Externally Led Patient-Focused Drug Development meeting with the U.S. Food and Drug Administration. The meeting featured testimony from adults with TSC and LAM, and one of the major themes was adults with TSC and/or LAM must make family planning decisions based on the possibility of passing on TSC to children and the exacerbation of their manifestations by pregnancy.
- **2022:** Following the World TSC Conference in Dallas, Texas, the TSC Alliance launched the Reproductive and Perinatal Health Task Force to focus on key priorities associated with maternal fetal pregnancy-related complications, mental health screenings and IVF safety. The Task Force held a workshop in March 2024, an important first step in creating evidence-based guidelines so families can make empowered decisions about their own reproductive health.

Building the infrastructure to impact clinical care

To unravel the complex mysteries of TSC, including the variability person-to-person and the progression of the disease throughout a lifespan, the TSC Alliance invested in building tools to empower researchers with the data and samples they needed to test new treatments. We also worked with clinicians from around the world to develop clinical standards of care that have evolved over time as we've learned more about the disease.

- **2006:** The TS Alliance launches the TSC Natural History Database to capture clinical data to document the impact of the disease on a person's health over his or her lifetime. An earlier version of the database was made possible through funding from the TSCRP. This is the first of two important tools that empower researchers to gain a deeper understanding of the progression of the disease.
- **2012:** The TS Alliance sponsors the first TSC Clinical Consensus Conference since 1998 to update the recommendations for diagnosis, surveillance and management of TSC. At the conference, the term "TSC-associated neuropsychiatric disorders (TAND)" is coined to describe the broad range of behavioral, psychiatric, intellectual, academic, neuropsychological and psychosocial manifestations. The neuropsychiatry panel goes on to recommend the screening of TAND annually leading to the creation of the TAND checklist.
- **2014:** The TS Alliance initiates a TSC Biosample Repository to collect high-quality biosamples, such as blood, DNA and tissues linked to detailed clinical data. More than 2,500 individuals are now enrolled in the Natural History Database, empowering researchers with the data and resources to begin to understand why TSC is highly variable person-to-person and to develop biomarkers to predict the severity of manifestations.
- **2019:** The TAND consortium launches the TANDem project to create a tool for families to complete the checklist themselves through an app on their phone and provide recommendations on surveillance and treatment. To support this project the TS Alliance adds a TSC Self-Report Portal to its Natural History Database in 2021 to collect

patient-reported outcomes and help determine gaps in care and unmet need. In 2023, the TAND consortium publishes international consensus guidelines for the identification and treatment of TAND, giving us a starting point to help connect families to existing therapies

- **2022:** Thanks to a generous \$2.5 million investment by the Ramesh and Kalpana Bhatia Family Foundation, the largest single gift in our history, the TSC Alliance launches Anya's Accelerator to uncover biomarkers, test new treatments and connect researchers with families to better address the root causes of TAND.
- **Today:** As part of Anya's Accelerator, the TSC Alliance is collecting blood samples and clinical data to identify blood-based markers that will help predict risk of TAND, progression, and response to treatment for TAND such as anxiety and autism.



"Anya's Accelerator will provide an opportunity to advance TAND research and innovation and offer hope for improved treatments, cures and prevention methods for those diagnosed with TSC and other neurological conditions."

—Anita Bhatia, MHA, CEO & Executive Director of the Ramesh and Kalpana Bhatia Family Foundation

Advocacy and community changing the course of TSC

As illustrated above, the TSC community has propelled research forward repeatedly through their advocacy and willingness to participate in clinical trials. Their influence is illustrated in the 40-year odyssey of vigabatrin from discovery to a preventative clinical trial.

- **1995:** Twenty years after vigabatrin is first synthesized, clinical trials start testing the use of the drug for the treatment of infantile spasms. So starts a two-decade long process of starts and stops to get the drug approved, including clinicians naming vigabatrin a first-line treatment

for TSC during the 1998 Clinical Consensus Conference and the drug changing hands in 2004.

- **2009:** During an FDA Advisory Panel Hearing, TS Alliance constituents advocate for approval of vigabatrin, which is finally approved by the FDA to treat infantile spasms, marking the longest approval process in the history of the FDA. Approval of vigabatrin would not have been possible without the heartfelt testimony of TSC families.
- **2012:** The TSC Clinical Research Consortium receives grants to initiate two clinical studies at five TSC Clinics to find biomarkers or signals that identify which newly diagnosed infants with TSC are at highest risk of developing infantile spasms by age two or signs of autism by age three. Three years later, they publish interim results for the EEG Biomarker Study in *Pediatric Neurology*, which shows that abnormalities in EEG of infants with TSC who have never had seizures are predictive of the risk of developing epilepsy.



Several TS Alliance constituents provided personal testimony during FDA hearings about Sabril in 2009.

“When Addie turned 6 months old, she saw a TSC specialist due to other diagnosable features of TSC. After an MRI, it was discovered she had ‘too many tubers to count’ in her brain and was suffering from infantile spasms. She was prescribed vigabatrin and within a few hours of taking the first dose, she has not had another infantile spasm since. Within a few days she began to smile and within two weeks she began to laugh again.”

—Karen Johnson, TSC mom who participated in the FDA hearing

- **2016:** The Clinical Research Consortium makes history with the PREVeNT clinical trial, the first-ever preventative epilepsy clinical trial in the U.S. Eighty-four infants enrolled in the study testing treatment with vigabatrin

to prevent the onset of epilepsy and improve cognitive outcomes.

- **2020:** Identifying an effective intervention is an important first step on the road to newborn screening in TSC. Another is the development of an assay to screen infants, so the organization hosts its first Innovation Workshop, bringing together experts from around the country to define the path forward to develop, validate and implement a newborn screening assay for TSC. Following the workshop, the TS Alliance awards two research grants to test novel hypotheses for screening for TSC.

The path forward has not always been straight, but the TSC Alliance and the TSC community time and time again have demonstrated resilience when overcoming adversity.

- **2023:** Results from the PREVeNT Clinical Trial are published in the *Annals of Neurology*. While intervention with vigabatrin did not improve neurocognitive outcomes, it did delay the onset and lowered the overall incidence of infantile spasms in infants with TSC. The study also provided a blueprint for future preventative clinical trials, including the TSC-STEPS study testing sirolimus as a preventative treatment for epilepsy in TSC, which began enrollment in 2021.

The path forward has not always been straight, but the TSC Alliance and the TSC community time and time again have demonstrated resilience when overcoming adversity. Today we stand on the shoulders of those who came before us as we brave new frontiers and take on the most challenging aspects of this disease. This is the next chapter of our story: 50 Forward.

Rothbergs partner with TSC Alliance for almost three decades

In 1997, Bonnie Rothberg, MD, PhD, MPH, MMM, FACP, reached out to what was then known as the National Tuberous Sclerosis Association (NTSA) when one of her children was diagnosed with TSC. Since then, she and her husband, Jonathan, have been stalwart partners and supporters of the TSC Alliance, especially the organization's research and education efforts spanning almost three decades now.

Bonnie went on to serve on the Board of Directors for six years in the early 2000s, and the Rothbergs have consistently helped fund several major research initiatives and conferences ever since; they've also supported many educational projects, including the TSC Alliance's Family and World TSC Conferences over the years.

Importantly, Bonnie created and implemented a groundbreaking survey in 2004 targeting families and individuals affected by TSC called "Patients Learning About the Natural Evolution of Tuberous Sclerosis" or the PLANETS study. The PLANET study's goal was to collect important information about how clinical symptoms associated with TSC evolve over an individual's lifetime. "The study asked questions about all aspects of how the disease impacts people physically, intellectually and psychosocially," Bonnie explains. "Then in 2006, we followed up with a second study that really focused on what is now known as TSC-associated neuropsychiatric disorders or TAND."

"At the time, I used the study as proof of concept for my Master's in Public Health thesis and wasn't expecting the response to be that large," Bonnie continued. "However, we ended up getting around 1,000 responses, which was huge, and it was wonderful to collaborate with the TSC Alliance on such an important project."

Bonnie was able to use the study results to write abstracts and present her findings at TSC Alliance conferences and a national American Society of Human Genetics conference. "What was most exciting, though, was my proof of concept became the motivation to create the TSC Natural History Database," Bonnie recalls. "And it showed there was substantial interest in the TSC community to support something like that."

PLANETS gave researchers and the organization information between 2003 and 2005, so she plans to now work with the TSC Alliance's science team see how her study's data might be compared to current data in the Natural History Database.

"At the time of PLANETS, mTOR inhibitors were being used in clinical trials so while a few study participants had experience with those, most didn't have the benefit of those drugs," Bonnie says. "This means we can now compare a population who didn't have access to mTOR inhibitors to the more current population that may use them across the lifespan. We can ask the question kind of like you would do in a high school reunion: where is everybody now?"



Because the Rothbergs have been involved with TSC for almost three decades, they also have seen an incredible amount of progress in treatment options and other successes due to the TSC Alliance's laser focus on moving research forward.

"My PhD mentor recently reminded me about why we do research," Bonnie says. "As a physician, your goal is to impact patients one at a time. As a scientist and an investigator, your life's work is to impact whole populations at a time. So for me, it's been very exciting to watch how the TSC Alliance and others started off with the basic TSC1 and TSC2 gene discoveries in the 1990s, followed by learning that both genes are part of a major cancer pathway and a major nutrition pathway and are also central to how cells manage themselves throughout the day."

Bonnie knows the real goal is to continue to search for a cure and develop new treatments that ultimately mitigate the symptoms people have because of TSC. "Those are absolutely important, and I've been really impressed with the different directions TSC research is taking these days," she continues. "These days it's much more than just having a pill to take so kidney angiomyolipomas and facial angiofibromas don't grow – now we are also focusing research on all the incredibly challenging behavioral issues we deal with on a day-to-day basis."

Bonnie believes the TSC Alliance, along with an extensive world-wide network of researchers and clinicians, are well poised to further research that will truly help families and individuals affected by TSC cope better and achieve their highest developmental potential. "The TSC Alliance is pretty much on the precipice of putting together a very large network of basic, translational and clinical science that will truly make a difference," Bonnie explains. "So, my family is excited to be able to take a leadership role in supporting those efforts."

"One of the great things about the TSC scientific community is that they are all friends, and everybody likes to work together, which is something you don't often see in science and academia," she continues. "It's been amazing to watch them work collaboratively, share the spotlight and move research forward as quickly and successfully as it has been. Being able to support that is an honor for my family and something we've always been compelled to do."

It's now been 27 years since the Rothbergs connected with the TSC Alliance. "When I joined the Board, I made a commitment that our family was always going to be there for the organization in different capacities and multiple ways," Bonnie remembers. "Now as we move into our second quarter century with the organization, we are really excited and honored to still be here and look forward to celebrating the TSC Alliance's 50th anniversary this year."

Government advocacy

Congress approves \$8 million for TSCRP, cuts funding for NIH

On March 23, after many months of budget stalemate, Congress finally approved the fiscal year 2024 Defense Appropriations Act as part of a larger package of spending bills. This legislation includes \$8 million for the Tuberosus Sclerosis Complex Research Program (TSCRP) at the Department of Defense (DoD) – the same funding level approved in fiscal year 2023. This funding brings the

aggregate appropriation for the TSCRP to \$121 million since fiscal year 2002!

The final package unfortunately did not include a bipartisan amendment offered by Representatives Jamie Raskin (D-MD) and Brian Fitzpatrick (R-PA) and agreed to in the House last September to increase funding for the TSCRP to \$10 million. The final package did not include any of the amendments adopted by the House that would have increased funding for the Congressionally Directed Medical Research Program (CDMRP), resulting in flat funding for all these programs.

Securing flat funding for the TSCRP occurred during what was perhaps the most difficult fiscal year since the inception of the program. Many federal programs received funding reductions in fiscal year 2024, including the National Institutes of Health (NIH), which was reduced by \$378 million below its fiscal year 2023 funding level.



TSC volunteers “March on Capitol Hill”

During the week of February 26, 120 TSC Advocates traveled to Washington, DC, to meet with their elected officials in Congress. Our advocates conducted 423 meetings with their Senators and Representatives both in person and virtually, requesting \$10 million for the TSCRP in fiscal year 2025. Our champions in Congress – Senators Martin Heinrich (D-NM) and Kevin Cramer (R-ND) and Representatives Brian Fitzpatrick (R-PA) and Jamie Raskin (D-MD) – will once again be circulating “Dear Colleague” letters in support of our request.

TSC Alliance hosts Congressional Briefing

On February 28 following a full day of advocacy on the Hill, the TSC Alliance held a Congressional Briefing in the Dirksen Senate Office Building with opening remarks by Senator Eric Schmitt (R-MO), the father of a child with TSC. Actor and long-time supporter Jim O’Heir served as emcee.

During the event, TSC Alliance Chief Scientific Officer Steven L. Roberds, PhD, gave an overview of the state of current TSC research, followed by Colonel Sarah Goldman, Director, Congressionally Directed Medical Research Programs, U.S. Army Medical Research and Development Command, who spoke about the impact of the CDMRP’s TSC Research Program. Next, Kimberly Raab-Graham, PhD, Wake Forest University School of Medicine, discussed how TSC relates to other disorders, then Mustafa Sahin, MD, PhD, Boston Children’s Hospital and TSC Alliance board member, explained how the impact of the TSC Alliance on research. The briefing wrapped up with Walter Koroshetz, MD, Director, National Institute of Neurological Disorders and Stroke (NINDS), giving an overview of how NINDS impacts TSC research, followed by closing remarks by TSC Alliance President & CEO Kari Luther Rosbeck.

How to get involved

If you’d like to play a role in the TSC Alliance’s government advocacy efforts, please join our Government Action Team by visiting tscalliance.org/actionteam or emailing grc@tscalliance.org today.



Congressional Briefing (L-R): Kimberly Raab-Graham, PhD; Mustafa Sahin, MD, PhD; Walter Koroshetz, MD; Colonel Sarah Goldman; Kari Luther Rosbeck; Bill Joseph; and Steven L. Roberds, PhD.



Jim O’Heir.



Senator Eric Schmitt (R-MO).

Reshaping the future of TSC

BY HEATHER LENS, TSC ALLIANCE BOARD MEMBER

On February 26, 2024, my daughter, my parents and I embarked on a journey with a purpose. Leaving Tulsa, Oklahoma behind, we headed to Washington, DC to advocate for the TSC Alliance. It all began in 2013 when our daughter, Madilyn Lens, started experiencing infantile spasms. Shortly after her first seizure, she was diagnosed with TSC, due to findings of tubers on her brain, heart and cysts on her kidneys. The news hit us hard; we felt utterly devastated and uncertain about what the future held for us with this condition.

Early on in Madilyn's diagnosis, I knew I wanted to get involved with the TSC Alliance. At the time, it was driven

by an attempt to control something when everything else seemed beyond my grasp. However, I soon discovered that despite being a rare disease, the TSC community and organization were powerful, and I wanted to be a part of it.

In 2015, I was invited to join the TSC Alliance in a grassroots effort to meet with Oklahoma representatives in Washington, DC, advocating for their continued support for the federally funded TSC Research Program (TSCRCP) at the Department of Defense. That year, I faced rejection from each of my representatives, leaving me angry and disheartened. But after allowing myself a brief pity party, I resolved to try



Heather and Madilyn Lens on Capitol Hill.



Madilyn Lens.

Young advocates at the Volunteer Appreciation Dinner.



again the following year. Persistence paid off, and we began to make headway with the Oklahoma delegation thanks to other Oklahoma families and their stories.

Participating in the March on Capitol Hill has always been a bittersweet trip for me. It was always so empowering but reliving the hard moments of this disease always left me depleted but also proud of our accomplishments.

This year to my delight, Madilyn expressed her desire to join as an advocate. As a mother, this thrilled me to no end. For years, I've been advocating on her behalf, so the possibility of her advocating for herself and others filled me with pride and excitement. I vividly remember the doctors telling me she'd never walk, talk or lead an independent life. Watching her advocate for herself and others in DC felt like such a monumental milestone.

What was even more remarkable was that Madilyn wasn't alone. There were numerous other children and adults with TSC marching the halls of Congress, sharing their stories. One particular moment during the advocacy training stood out, as each volunteer stood up, stating their name and connection to TSC. It was incredibly inspiring and heartwarming to see so many individuals with

TSC advocating for themselves, from young children to remarkable adults.

On our first day in DC, Madilyn was understandably nervous about sharing her story. However, after meeting with a compassionate legislative assistant, she found her voice and courageously shared why supporting the TSCRP was crucial. She even highlighted that she's on medication that originated from the TSCRP. Additionally, she enjoyed participating in the Volunteer Appreciation Dinner night, dressing up in her poodle skirt and having a blast with her fellow TSC friends.

Meeting Jim O'Heir was another highlight for Madilyn. Having sent him artwork and messages on Facebook over the years, finally meeting the TSC champion in person was incredibly meaningful for her. Overall, this advocacy trip was truly a once-in-a-lifetime experience. The memories we created were priceless and witnessing Madilyn's newfound confidence left me overwhelmed with gratitude.

Advocacy knows no age limits or boundaries. I'm immensely thankful for the amazing community and the TSC Alliance. Not only are they reshaping the future of TSC, but they're also nurturing young leaders like Madilyn. Together, we're making a difference, one step at a time!

50th anniversary gala scheduled for October 25



The logo features a large '50' with a gradient from orange to blue. Inside the '0' is the TSC Alliance logo. Below the '50' are the years '1974' and '2024'. At the bottom, the word 'FORWARD' is written in large, bold, blue letters. Below that, the text reads 'An Evening of Progress and Promise', 'Friday, October 25, 2024 | 6 – 10 PM', 'Cipriani 42nd Street, NYC', and 'tscalliance.org/50gala'.

and ensuring anyone affected by TSC has access to care and treatment. David and Penney have devoted much of their lives to making sure everyone with TSC, including their son Eric, have the best possible outcomes. They have both been crucial to the TSC Alliance's focus on transition resources and housing options for semi-dependent adults with TSC.

Ramesh and Kalpana Bhatia Family Foundation



The **TSC Champion Award** honors the Ramesh and Kalpana Bhatia Family Foundation, recognizing their leadership around TSC-Associated Neuropsychiatric Disorders (TAND), an unmet need within the TSC community. The Bhatia Family Foundation launched Anya's Accelerator, aimed at catalyzing the development of biomarkers to inform clinical care and development of interventions for autism and other impactful aspects of TAND. Their work has galvanized a global community of researchers to come together in support of greater progress.

On Friday, October 25, the TSC Alliance will host our 50th Anniversary Gala, **50 Forward: An Evening of Progress and Promise**, at Cipriani 42nd Street in New York City from 6 to 10 pm. Nobelpharma America, LLC, and Jazz Pharmaceuticals are the event's Gold Sponsor.

Co-Chaired by TSC Alliance board members Jonathan Goldstein and Laura Marks, the gala will help celebrate five decades of progress and promise, highlighting milestones while looking forward to the future. Joy and Chris Dinsdale will serve as Honorary Chairs. TSC Alliance founders Adrienne Cohen and Susan McBryne are also on the Honorary Committee.

Honorees

During the 50th Anniversary Gala, we'll pay special tribute to families, individuals and a company who have each made a tremendous impact in the fight against TSC.

David and Penney Parkes

Courage in Leadership Award presented in recognition of the Parkes' three decades of unwavering service to the TSC community, including providing leadership on our Board of Directors, offering peer support, guiding strategic planning and marketing initiatives, volunteering for every major NYC event



Nobelpharma America

The **TSC Champion Award** is presented in recognition for their efforts—even during a global pandemic—to gain FDA approval of the first topical treatment for facial angiofibroma associated with TSC. Nobelpharma America's mission is to contribute to society by developing critical but neglected pharmaceuticals and medical devices. Their mantra, "When in doubt, the patient's benefit takes priority," is evident in their approach to overcoming challenges throughout the product development process.



The PREVeNT Trial Core Team (Drs. Martina Bebin, Jurriaan Peters, Brenda Porter, Darcy Krueger, Sarah O’Kelly, Hope Northrup, Mustafa Sahin, Gary Cutter)

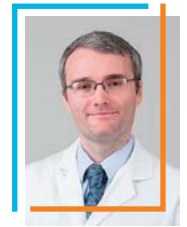


Progress in Research Award for their advancement in clinical research by implementing the first preventative clinical trial for epilepsy in the United States aimed to prevent or delay seizures in infants with TSC. The PREVeNT Trial results suggested that rapid diagnosis of TSC in infants, prior to the onset of seizures, followed by close and frequent neurologic follow-up including serial EEGs, aids in early detection of those infants at risk for seizures. The initiation of vigabatrin at the onset of epileptiform activity on the EEG does delay and decrease the

overall prevalence of infantile spasms. The frequent neurologic follow-up in the first year for a TSC infant improved the likelihood of early detection of both focal seizures and infantile spasms, which is critical for ensuring the best developmental outcome possible. This team of researchers designed a cutting-edge clinical trial that will serve as the foundation for future studies focusing on preventative treatment in TSC.

Derek Bauer, MD

Promise in Research Award in recognition of his work as an adult neurologist specializing in TSC care, serving as a member of the Reproductive/Perinatal Health Initiative’s Core Group, Chair of the Outreach Committee and on our Board of Directors. Dr. Bauer uses his experience as an adult living with TSC to enhance the TSC Alliance’s outreach and educational efforts focused on the adult population. His expertise is also crucial for our global relationships.



Plan now to join us

Visit tscalliance.org/50gala today to get tickets for early bird pricing; it’s night you won’t want to miss! Tickets are available for individuals, couples and tables of 10. You can also purchase tickets to sponsor TSC community members or various levels of sponsorship.

TSC Academy introduces new course

TSC Academy is a free online educational platform created to increase scientific knowledge about tuberous sclerosis complex in a digestible way. The platform features lessons about the basic, preclinical and clinical science of TSC, how research helps us understand and treat the disease, and the importance of the TSC community voice in advocating for TSC research and care within the federal, state and local governments.

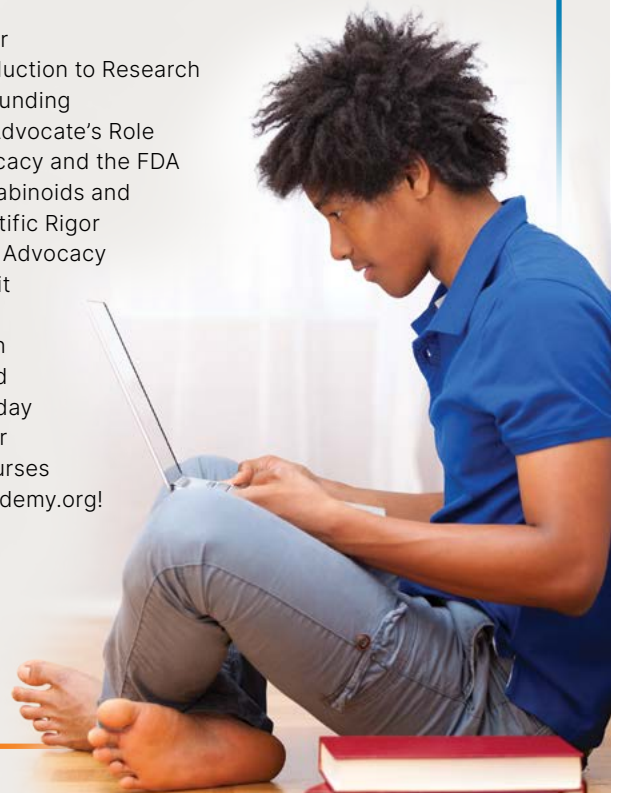


Recently, we launched a new course called *TSC Clinical Consensus Guidelines*. This course aims to give an overview of the importance of the International Tuberous Sclerosis Complex Diagnostic Criteria and Surveillance and Management Recommendations, how they can be implemented and used as a tool in advocating for TSC care.

Other TSC Academy courses include:

- Primer
- Introduction to Research and Funding
- The Advocate’s Role
- Advocacy and the FDA
- Cannabinoids and Scientific Rigor
- Local Advocacy Toolkit

Learn more and enroll today to see our latest courses at tscacademy.org!



Board Chair Bill Joseph welcomes community leaders to the TSC Alliance Summit.



community leadership



TSC Alliance Summit



Highlights from the 2024 TSC Alliance Summit

The 2024 TSC Alliance Summit was held from February 27 through February 29, 2024. Along with our staff and Operating Board and Endowment Fund Board members, more than 100 volunteer leaders from across the country raised awareness and advocated for federal funding for TSC research during the **March on Capitol Hill** with the goal of visiting each Congressional office in person or virtually (read more about these efforts on page 13).

We also hosted in-person **Volunteer Leadership Training** sessions to educate our community about the current state of TSC research; tools they can use to better support their communities; the redesigned TSC Alliance website; and brainstorming sessions to effectively organize educational events, community gatherings and fundraisers. 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.

On Thursday, February 29, both the TSC Alliance Board of Directors and the Endowment Fund Board of Directors held

their annual Spring committee and full **Board of Directors Meetings** throughout the day.

The week ended with our annual **Volunteer Appreciation Dinner**, which had a 1950s theme. During the dinner, the TSC Alliance honored our dedicated community members and volunteers for their tireless efforts and advocacy for TSC research as well as Chief Outreach Officer Jaye Isham with a 20-year service award. Congratulations to Franny Award (Volunteer of the Year) winners Shalonda Alexander, Lisa Huddleston, Kari Ihle and Bridgett Claxton-Langstaff. We also presented the Keith Hall Distinguished Leadership Award to Jonathan Goldstein and a Lifetime Achievement Award to Marion Adams.

Thank you to our generous supporters for making the Volunteer Leadership Summit possible, including Presenting Sponsors Jazz Pharmaceuticals, Marinus Pharmaceuticals, Nobelpharma America, LLC and Neurelis; Champion Sponsors Aeovian Pharmaceuticals, Inc., Al Marshall and UCB; and Supporting Sponsor Upsher-Smith Laboratories, LLC.



Kari Luther Rosbeck presents a 20-year service award to Jaye Isham.



Lifetime Achievement Award recipient Marion Adams (center) with Frank Gallagher (left) and Andy Bott (right).



Franny Award winner Shalonda Alexander.



Franny Award winner Kari Ihle.



Franny Award winner Bridgett Claxton-Langstaff.



Franny Award winner Lisa Huddleston.



Shelly Meitzler presents the Keith Hall Distinguished Leadership Award to Jonathan Goldstein.



TSC Clinics “Up Close” TSC Center of Excellence at Seattle Children’s Hospital

Top Row (L-R): Jackie Lee Eng (TSC Research Coordinator), Stephanie Randle (Epileptologist), Kiana Siefkas (Genetic Counselor). Bottom Row (L-R): Jeff Avansino (Parent and Surgeon), Claire Kennedy (TSC Clinic Coordinator), Susanna Fenstermacher (Neurology TSC ARNP), Alison Cantarano (TSC Nurse), Mikaela Morales (TSC Research Coordinator), Lucy Vela SanPedro (TSC Clinic Scheduler), Joseph Flynn (TSC Nephrologist).

The TSC Alliance has recognized the TSC Clinic at Seattle Children’s Hospital since 2017; in 2023 it became a recognized TSC Center of Excellence (COE). This article continues an interview series about the healthcare teams around the world who provide excellent care to individuals and families with TSC.

Seattle Children’s TSC Center of Excellence is directed by Stephanie Randle, MD. The TSC Clinic is part of Seattle Children’s Hospital nationally ranked Neuroscience Center. The multidisciplinary team spans many sub-specialties, including but not limited to neurology, neurosurgery, neuropsychology, nephrology, dermatology, ophthalmology, genetic counseling and cardiology.

We interviewed Dr. Randle about the Seattle Children’s Hospital TSC Clinic Center of Excellence.

Q: What motivated you to choose this career path in TSC?

As a child, I was interested in the field of medicine and, at an early age, knew I wanted to specialize in neurology. My mother was a Special Education teacher, and I grew up volunteering in her classroom. This helped drive my passion for

pediatrics and working with children with neurodevelopment differences. I studied neuroscience in college and worked for four years in a neuroscience research lab studying children who had early strokes. While working as a pediatric neurology resident at Seattle Children’s Hospital, I diagnosed an infant with TSC who had new onset seizures. The mother had TSC but had very little understanding of what this meant and was not receiving care. I got to work with the mother as well as her child, encouraging her to seek adult care for her own diagnosis alongside her child’s care. This was a very rewarding and validating experience, and when I went through my epilepsy fellowship, I knew I wanted to grow TSC care at Seattle Children’s Hospital. I love that I get to follow my patients into young adulthood, allowing me to get to know the families very well.

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

I have a fantastic TSC team in neurology. This is comprised of our TSC clinic coordinator, Claire Kennedy, who ensures that all of our patients with TSC are receiving the care they need and keeping in contact with our families. Our clinic scheduler, Lucy Vela SanPedro, is amazing at complex scheduling, making

sure we can coordinate as much as possible for our patients. We're lucky that Lucy can schedule not only Neurology appointments, but also imaging and EEG appointments, helping keep patients on track for the care they need. Alison Cantarano is our lovely TSC nurse who is always quick to reach out to families and make sure that we get questions answered for families outside of their clinic appointments. Susanna Fenstermacher, ARNP, and I share our TSC patients and work together to provide the best care possible. We have multidisciplinary clinic days, which allow doctors in the different TSC specialties to get together and update each other on care practices. This helps keep the whole care team connected and communicating.

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

I give a few talks per year, and my most recent was to primary care providers in the WWAMI (Washington, Wyoming, Alaska, Montana and Idaho) region about TSC awareness and information about Seattle Children's Hospital's TSC Program. Our clinic is one of the only in the region for TSC care, so we see patients from all of the surrounding WWAMI region. Every year, we form a team for the Step Forward to Cure TSC walk and have been the largest clinic fundraiser for the past two years! We also try to feature families with TSC in the Seattle Children's Hospital newsletter regularly.

Q: What are the most challenging aspects and most fulfilling aspects of your clinic work?

The hardest part, as an Epileptologist, is caring for patients with difficult to control seizures. It can be challenging to find the best treatment plan for a specific patient as every individual with TSC is unique. The most fulfilling part is definitely

the relationships I have with the families I help treat. Our clinic follows almost 200 kids, and I get to see the progress from day one diagnosis onward, improving each person's life as best we can through treatment options.

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

I work very closely with our neuropsychology team, who are able to see most kids diagnosed with TSC for consult, whether or not there immediately appears to be concern for the presence of TAND. We do this in hopes of diagnosing kids that do have TAND as early as possible to set them up for success down the road. Treatment options for TAND can be tricky, and we rely on our social work team and the community to get these resources available to as many families as possible.

Q: TSC is considered a linchpin disease, meaning every advance made in TSC research may benefit other diseases, such as epilepsy, autism and cancer. Is there anything upcoming in research that excites you not only for TSC, but for other related diseases as well?

I'm excited about the TSC-STEPS study, as it really has the potential to change how we approach TSC patients' treatment plans. At Seattle Children's Hospital, we currently have a study ongoing that looks at the use of HASTE MRI, which is a quick MRI that doesn't require sedation, and comparing it to full MRI to see if it is sufficient for diagnosing SEGAs and/or tracking SEGA growth. This is exciting because if HASTE MRI proves sufficient, it could decrease cost, wait time and stress associated with traditional MRI. More generally, I'm excited about the potentials of gene therapy, as I believe it could be the future for treatment of TSC. I'm looking forward to seeing these develop.


Q: What do you enjoy doing outside of work?

I have lived in Seattle since 2012, and I love it here. It's great to have so many outdoor options available year round. I enjoy being active, hiking and paddle boarding on Lake Union. My husband, Brett, and I love going on adventures with Cleopatra, our two-year-old Boston Terrier. We have been very fortunate to be able to travel as well and recently explored the Bavarian Alps. I would love to become fluent in French one day! To unwind, I enjoy reading and started a book club in January 2023. It has been a wonderful way to connect with friends and discuss interesting books.

Q: Anything else you'd like to share?

I'm very proud that our clinic became a COE this year. I started the program in 2016, thanks to assistance and support from Seattle Children's Hospital, specifically, Dr. Jeff Avansino. He is a surgeon at Seattle Children's Hospital who developed a multidisciplinary clinic of his own and was able to provide me with guidance that I needed to develop our program. He also has a son with TSC and knows the importance of coordinated care. I am thankful to my families to allow me to care for their loved ones. In the future, we're hoping to expand into having an associated adult program at the University of Washington to improve patient care as they transition into adulthood.





Has your life changed? Then so should your will

Ever look at the calendar and marvel at what year it is? Has that much time *really* gone by?

With time's passage comes change: Babies are born, loved ones depart. We move to a new town, start a new job. Laws get revised. We discover a new passion, a new cause. When changes happen, it's important that your will reflects them. Here are key categories to consider:

- **Timing:** Did you write your will prior to 2001? A lot has changed in the world of estate taxes. For example, the amount you can leave to heirs without paying federal tax is much higher than it was years ago. It's up to \$13.61 million in 2024.
- **Relationship status:** A change in your marital or long-term relationship means you may want to alter your will and beneficiary designations.
- **Children:** Perhaps you now have children or grandchildren, and you want to ensure you have provided for them. Or, you created a will when the kids were young, and they are now grown and financially stable.
- **Residence:** Legal requirements and taxes vary by state. If you've moved to a new state since creating your will, you'll want to see what impact that may have.
- **Family and friends:** Our connections with people sometimes shift over time. You may want to increase or decrease the amount left to certain individuals or add and remove them from your will or beneficiary designations.
- **Pets:** Ensure your pets are taken care of after you're gone. Name a guardian you trust and assign any assets to provide for your pet's food and veterinary care.
- **Charitable causes:** If you have formed connections with certain nonprofits and want to take your support to the next level, you can set up gifts in your estate plan to ensure your values endure after your lifetime.

No plan? Start today!

If you don't have an estate plan, don't worry – you're not alone. The good news is that now is a great time to get started. Here are the basic things your estate plan should include to give yourself and your loved one's peace of mind:

- **Will and/or trust:** Your will determines how your property is distributed after you're gone. A trust sets up how your assets are managed and distributed.
- **Beneficiary designations:** Names the person(s) or charities you want to receive a specific asset, such as retirement plan assets or life insurance.
- **Power of attorney for finances:** Gives a trusted individual authority over financial decisions if you are unable to make them.
- **Power of attorney for health care:** Names a person to ensure your health care wishes are followed in the event you are unable to do it yourself.
- **Advance health care directive (aka living will):** Documents your wishes to a doctor regarding life-sustaining care.

6 reasons to update your plan: A checklist

If any of these statements apply to you, don't wait another day – contact an estate planning attorney or use an online planning tool to make changes.

- I am a new parent or grandparent.
- I've started or ended a long-term relationship with an individual named in my estate plan.
- I'd like to change who is provided for after I'm gone.
- I now own a business.
- I'd like more of my estate to go to my loved ones instead of taxes.
- I want my estate to support my favorite charitable causes.

When creating or updating your will and other parts of your estate plan, we hope you consider the role TSC Alliance has played in your life and how you can continue making a difference for years to come. Contact Lisa Moss, Vice President, Donor Relations, at lmoss@tscalliance.org or (301) 562-9890 today to discuss your giving options. You can even use our new free will tool called Giving Docs, available online at tscalliance.org/GivingDocs.

Honorariums (September 1, 2023 – February 29, 2024)

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.

- Tribute(s) for Alexander P. Ackerman**
Mr. and Mrs. Doug Ackerman
- Tribute(s) for Ried T. Ackley-Munson**
Mr. Robert Miner
- Tribute(s) for Henry Albers**
Mr. and Mrs. James S. Tart
Mr. and Mrs. William G. Vreeland III
- Tribute(s) for Rocco Alex**
The Alex Family
Mrs. Carmela Spinoso
- Tribute(s) for Yusuf Alkurta**
Ms. Melanie Wipf
- Tribute(s) for Kristen A. Aller**
Mr. Gordon L. Felger
- Tribute(s) for Sophia Almeida**
Mr. and Mrs. Virgil Spanier
- Tribute(s) for David C. Anderson**
Anonymous
- Tribute(s) for Mary Anderson**
Mr. and Mrs. John J. Caha
- Tribute(s) for Rebecca Anhang Price**
Mr. Justin W. Timbie
- Tribute(s) for Cynthia Arcuri**
Ms. Kari and Mr. Chris Rosbeck
- Tribute(s) for Marcia Ardit**
Mr. and Mrs. Phillip Ardit
- Tribute(s) for Luke Avansino**
Mr. Aaron Howes
- Tribute(s) for Georgiana B**
Anonymous
- Tribute(s) for Emmaus Ballew**
Mr. and Mrs. Jeffrey C. Hunter
- Tribute(s) for Bobbie Baranowski**
Ms. Carolyn Baranowski
- Tribute(s) for Xavier Barr-Malec**
Mr. and Mrs. Robert Tyler
- Tribute(s) for Mac Allen Bassett**
Elizabeth Green
- Tribute(s) for Jack Beard**
Mr. and Mrs. Dave Hines
- Tribute(s) for John R. Beattie**
Dr. and Ms. Thomas W. Beattie
- Tribute(s) for Patrick Beatty**
Mr. and Mrs. Ralph T. Beatty
- Tribute(s) for Josh P. Beck**
Ms. Karen White
- Tribute(s) for Marigold Beck**
Ms. Kathryn Polcrack
- Tribute(s) for Frances Beebe**
Mr. and Mrs. Michael Webb
- Tribute(s) for Parker C. Beebe**
Anonymous
Ms. Connie Conley
Mr. Gilbert H. Emory
Ms. Dorothy S. Hopkins
Ms. Anne M. Manaraze
Mrs. Patricia Manzi
- Tribute(s) for Daniel Beldner**
Mrs. Irene Marton
- Tribute(s) for Heather Benson**
Mr. David Biernbaum
- Tribute(s) for Rebecca L. Berger**
Dr. Patrice M. Becker, MD
- Tribute(s) for Haley Berry**
Dr. Patricia Evans
- Tribute(s) for Anita Bhatia**
Ms. Kari and Mr. Chris Rosbeck
- Tribute(s) for Jacob Blood**
Anonymous
Mr. and Mrs. William S. Blood, Sr.
- Tribute(s) for Julie Bloom**
Cliff and Deborah White Family Foundation
- Tribute(s) for Kristen A. Bloomfield**
Mr. and Mrs. Robert M. Jackson
- Tribute(s) for Justyne Bocus**
Ms. Krista Bocus
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